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ABSTRACT

This publication contains five action papers presented at the New York City seminar on November 10-12, 1980. Each paper is presented separately as a chapter organized according to this format: summary comments; the paper itself; selected excerpts of reviews, comments, and questions of the Fellows who wrote and presented the papers; and summary of recommendations. These topics are considered in the papers: (1) institutions/service systems for disability prevention and rehabilitation; (2) prevention of human disabilities and recommended policies and practices for the 1980s; (3) the reality of disability and its socioeconomic impact on the third and fourth worlds, including twelve principles underlying application of the rehabilitation process in any society, practical suggestions for implementing the process in developing countries, and list of needed research; (4) integration of disabled persons into their society; and (5) overview of mechanisms which have currency in dissemination of rehabilitation information with appended lists of 2 agencies concerned with disability and/or information dissemination. A final section presents excerpts of reviews and comments from international rehabilitative and health care experts on the five action papers. (YLB)

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International Aspects of Rehabilitation Of Disabled Persons: *Policy Guidance for the 1980s*

A Report of the Fifth Mary E. Switzer Memorial Seminar

MARCH, 1980

EDITOR: LEONARD G. PERLMAN, Ed.D.

U S DEPARTMENT OF HEALTH, EDUCATION & WELFARE
NATIONAL INSTITUTE OF EDUCATION

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"The horizons ahead where rehabilitation can be the cutting edges of progress are broad and golden. There is no limit to the groups of people who can be helped and served by this program. The limit lies only in the need for knowledge to deal with the unsolved problems. We are still lacking an organized approach, in many areas which we must have before we can follow the road so successfully cleared by the rehabilitation leaders of the past."

Mary E. Switzer
Journal of Rehabilitation, September, 1970

Foreword

First, I want to say to you what a happy and profitable time this has been for us to have you here these three days. As I said in the beginning, I can feel Mary's presence in the deliberations - she just seemed to be everywhere and from my vantage point its been a most successful meeting.

I was asked to make some remarks for the publication which could be published as extemporaneous reflections.

A friend sent me an article this morning containing excerpts from the remarks of the president of Yale University in the **Washington Post,** October 23rd edition regarding changes in the policies and practices in *OMB and HHS. In this article he points out that **Science Magazine** estimated that, at Stanford University alone, these new regulations would require an increase of 80,000 reports annually and from $250,000 to $300,000 to put in place a new reporting system at one university. I think this pretty well puts in focus one of the real problems we are in. We are thinking too much about paper and not enought about people. We're all covered with paper and we don't have time enough to think or to be with our clients and our patients.

I was asked many months ago what I thought the greatest advance in rehabilitation had been in the last 25 years. I didn't have to think about it, because my answer was a reflex one. I think people expected me to talk about new techniques, new hardware, new paramedical types of organizations, but I don't feel that these were the greatest advances at all. I think the greatest advance we have made since I started in this program thirty years ago has been the recognition of a responsibility toward disabled people. We have that responsibility to help them to live the best lives they can with what they have left. We learned early on the fundamentals - that arms, legs, eyes and ears and bodies do not make a person - spirit makes a person. We learned too that today, certainly in our world, we do not pay for strength, we only pay for two things - the skill in your hands and what you have in your head. We've also learned that, because nature has given us such tremendous powers of over-compensation, there can be an advantage and a disadvantage. The blind man makes above average use of his senses of touch and hearing. Put him in a position where he can use those over-developed abilities and he may be better than the "normal" person.

I have been excited to see what has happened to the quadriplegics in the Institute for Rehabilitation Medicine (IRM) program through these years. I got a letter last week from the first quadraplegic we had in this program up in the old loft building at 38th Street. He was a patient in 1949. He is still alive, he is still at work, he's had a good life. He has a fine family and this, to me, getting this letter and report after all these years, was very exciting. Again, I have seen in spinal injury patients through the years a phenomena that has been both exciting and rewarding to me and that is that many of these individuals, especially the highly athletic ones, I've seen those who had to have tutors and special examinations and what not in order to stay eligible for football or other sports - I have seen them go through the normal depressions that comes with this type of catastrophic injury. And, then I have seen them go through a sort of transmutation, if you will, and something at a given time changes. They say to themselves, I know I can't compete with my arms and legs anymore, but I have a good head that I have never used and from now on I will compete with my head.

I have used an old aphorism for many years that you "don't get fine china putting clay in the sun - you only get it if it goes through the white heat of the kiln." In the firing process some pieces are broken. Life breaks some people -disability makes some people. However, if through courage, help and dedication you can go back to a new life again, you can never be clay again, you're porcelain.

I have often been asked why I seem to get such deep satisfaction out of working in this program through the years. I was one of the fortunate ones. I didn't come into this program because there had been a tragedy in my family. But I saw what could be done and I had to do what I did as best I could. I talked about the depth of spirit and if you work with these people a little of it is bound to rub off. And I think that the understanding that we get from working with the severely disabled is the great reward and satisfaction of the program.

In the early days you couldn't use the word rehabilitation in a title for a presentation at a medical meeting; nobody would come because they did not know what rehabilitation was. So I had a stock title I used, SICK PEOPLE IN A TROUBLED WORLD and you'd get a few people out because they thought it was a new pill or a new technique and then once you got them in the hall you could talk to them and they would sit and listen. I used it for many years and a few months ago I sent the title up to a university where I was to speak and the chairman in the introduction said, "This is a wonderful title, but I wonder whether it should be TROUBLED PEOPLE IN A SICK WORLD."?

The thing that distresses me I think the most in the health field is that we have become so technologically precocious and yet so spiritually adolescent. I think we tend to forget the fundamental necessity of understanding and love and compassion in the management of our patients. I think by and large we do a better job than we do in medicine and health care in general because I think we have a chance and opportunty to deal more closely with the individual. I ran across a quotation the other day which I haven't had out of my pocket because to me it said it so beautifully. It is by Eric Hoffer who you remember was a stevedore and self-educated and a self-made person and now writes for the **Saturday Review** and is on their staff and this is what he said, "Almost all noble attributes - courage, love, hope, faith...loyalty - can be transmuted into ruthlessness. Compassion alone stands apart from the continuous traffic between good and evil...within us. Compassion is the antitoxin of the soul." And I think that we in our field doing all of the technical things that we are doing must remembr that, at least in my opinion, compassion is our great tool for serving our fellow man.

We have dedicated ourselves to use this tool and that is exactly the way that Mary Switzer felt. I think that was her fundamental feeling about people, love and compassion.

This Seminar, as a memorial tribute to Mary Switzer, comes at a most opportune time as we enter the International Year of Disabled Persons. I hope that the monograph of the three days of deliberations will provide awareness and direction to the many individuals working to improve the lives of persons throughout the world.

Howard A. Rusk, M.D.
Distinguished University Professor
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Note: The above are from closing remarks made by Dr. Rusk at the Memorial Seminar.

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Many persons played vital roles in the planning and success of the Fifth Memorial Seminar and appreciation is expressed to Brockman Schumacher, Ph.D., Chairperson of the Switzer Memorial Committee, and the Committee members; Dr. Robert Brabham, Chairperson of the NRA Commission on Professional Concerns; David Mills, NRA Executive Director and his fine staff for their constant support and to the President of NRA, Joseph Dusenbury.

Special thanks go to Howard A. Rusk, M.D., President of the World Rehabilitation Fund for hosting the Seminar and to his efficient staff for the handling of the numerous details involved in this project; to James F. Garrett, Ph.D., Vice-President of the World Rehabilitation Fund, for his excellence in chairing the Seminar; to Gerry R. Perlman for editorial assistance with the monograph; James E. Gorman and Richard Dietl for preparing the final copy of the monograph; to the expert reviewers from many countries; and of course to the Mary E. Switzer Fellows whose ideas and recommendations are presented in this text.

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Definitions of Impairment, Disability and Handicap*

An understanding of the concepts of impairment, disability and handicap, and of the relentless escalation from one to the other, is necessary in planning efforts directed toward prevention and rehabilitation. For this purpose, WHO, in its revised policy for disability prevention and rehabilitation, has defined those concepts as follows:

"**Impairment:** A permanent or transitory psychological, physiological, or anatomical loss or abnormality of structure or function.

"**Disability:** Any restriction or prevention of the performance of an activity, resulting from an impairment, in the manner or within the range considered normal for a human being.

"**Handicap:** A disability that constitutes a disadvantage for a given individual in that it limits or prevents the fulfilment of a role that is normal depending on age, sex, social and cultural factors, for that individual."

Within these definitions the following clarifications may be made:

(a) An **impairment** may be a missing or defective body part, an amputated limb, paralysis after polio, restricted pulmonary capacity, diabetes, nearsightedness, mental retardation, limited hearing capacity, facial disfigurement, or other abnormal condition;

(b) s**Disabilities** as a result of an impairment may involve difficulties in walking, seeing, speaking, hearing, reading, writing, counting, lifting, or taking an interest in and making contact with one's surroundings. Just as impairments may be permanent or transitory, so disability may last for a short or long time, may be permanent or reversible, may be progressive or regressive and may vary in its impact from the demands of one situation to another; and

(c) A disability becomes a **handicap** when it interferes with doing what is expected at a particular time in one's life. Children with disabilities may become handicapped in caring for themselves, engaging in social interactions with other children and adults, communicating their thoughts and concerns, learning in and out of school and developing a capacty for independent economic activity.

Introductory Remarks From the Seminar

By James R. Burress, Ed.D.*

I am pleased to have the privilege of making introductory remarks as one of the Fellows in this Seminar. I am especially delighted to be a part of this program as it brings together in several important ways my ten-year involvement in an international effort to focus attention on the economic and social conditions of disabled people. Mary Switzer played an important part in turning my attention to the world scene and the then emerging important developments tending to place the population of handicapped people in a more important light.

I was especially pleased that the Planning Committee agreed to emphasize international rehabilitation as the focus of this Seminar. It is most timely as it closely follows the series of United Nations' proclamations and the several activities supporting an International Year in which the world's attention will be directed to the circumstances of probably one-half billion disabled people populating every nation on earth.

I need not remind my "Fellows" here that disabling conditions are a common denominator cutting across racial, political and cultural differences bringing the disabled person and those who would assist him, into a kinship that knows no territorial boundaries. We also know that the development of services for disabled people has been and will continue to be a positive means of reaching the minds and hearts of all people and perhaps of greater importance is the achievement of international understanding.

The economics and resources of the nations of the world today are such that the needs of handicapped people receive a low priority in national and international planning and then only passing attention.

Ever increasing masses of handicapped people, young and old, are surviving on limited family resources, strained public welfare resources, and existing all too often as beggars.

More enlightened, humane and concerned national and international organizations, both public and private, are recognizing that productive and competitive persons although handicapped can be economic and social assets.

I know that many of you have heard me say that "the quality of life in our civilization will be measured by the caring we reflect as we seek to eliminate suffering among less fortunate handicapped and disadvantaged people in our time."

I have read the five "action papers" with much personal interest. I have looked for substance in these presentations which would help point a new way to strengthen international concerns and strategies for relieving the suffering and for increasing opportunity for a good life for all disabled people. I quickly add that I am also seeking the political and economic strategies to achieve these goals through the active organization, participation and leadership from within the ranks of disabled people. I hope that we can share in greater depth the management of national and world movements through which these goals may be achieved.

I know that these were the great concerns of Mary Switzer. She expressed them in her quiet hours with close associates and friends as well as in her many public activities. In the September/October 1970 issue of the **Journal of Rehabilitation**, Mary Switzer stated, "In rehabilitation, as in all social programs today, time presses in on us. National and world movements outside our own specific concerns affect those concerns, and challenge us to be alert to the obligation the rehabilitation community has, to share its technology, its philosophy, its commitment -- even more, to insist that rehabilitation play its maximum eloquent role in the development of public policy, and be the probing conscience of private and voluntary movements to help- dependent people.

"The horizons ahead where rehabilitation can be cutting edges of progress are broad and golden. There is no limit to the groups of people who can be helped and served by this program. The limit lies only in the need for knowledge to deal with the unsolved problems. We are still lacking an organized approach, in many areas, which we must have before we can follow the road so successfully cleared by the rehabilitation leaders of the past."

Further in speaking of the 10th Anniversary of Rehabilitation International Research Program, Mary stated that, "We have seen in this decade the influence of the association of many people of different cultures coming together to discuss the best way to handle disability. We have seen how the language of rehabilitation becomes an international language. It breaks down barriers; it transcends political beliefs, geographical boundaries, and even language.

"Despite the destructiveness of war and deprivation, the chaos of civic revolt and protest, the violence of natural disasters, rehabilitation has consistently emerged over the years as the force that heals. Rehabilitation joins men and nations together, that they may begin again and move closer toward shared dreams of freedom and opportunity. Rehabilitation has always been a major instrument for brotherhood."

Mary Switzer's words spoke eloquently to her contemporaries of the need for world attention to the needs of disadvantaged and disabled people. Her presentation at the Rehabilitation International Congress in Dublin in 1968, brought into clear focus our responsibility for promoting a world consciousness of the need for special international attention by many millions of disabled people. In her closing remarks to the International Congress, she pointed out that "there is no escaping the fact that today rehabilitation means far more than physical, mental and vocational restoration. Its philosophy and methods are essential in the process of healing the wounds of social and economic deprivation."

"Second, the rehabilitation community must continue to work for the principle that governments implant rehabilitation concepts into all national programs of social development. This is primarily humanitarian and, therefore, morally and ethically sound. But it is also good economics. The cost of mushrooming dependency is far greater than the cost of rehabilitation, both in human terms and as a matter of practical fiscal administration.

"Third, the rehabilitation community does not exist in a vacuum. It needs and must invite public interest, involvement, and support. In turn, it must evidence willingness to involve itself in the political and social needs and drives of nations and communities.

"And, finally, rehabilitation must provide the opportunity for full participation by its clients in the planning, developing, and operation of social and rehabilitation service programs.

"If I were to leave one urgent plea with this conference, it would be to charge the affiliates of the International Society to explore ways of adapting these four points to the circumstances of their various nations; then, to work more diligently than ever to continue the task of broadening the rehabilitation process begun so valiantly half a century ago. Rehabilitation can serve as the conscience of the world. We must make the good things work -- for all men. To do this, it is crucial to believe -- really to believe -- that all people want to be self-sufficient, that no one is totally disabled or disadvantaged, or totally advantaged." These words were spoken by Mary Switzer over a decade ago.

I may seem somewhat idealistic in my perceptions of the great potential for disabled people in the world today. I am, to some extent, and I believe we must be if we are to keep some sense of perspective and perception as we consider the impact of meeting the needs of one-half billion people. The stark reality of our capacity to make much of a change in the life circumstances of these people is made very clear in Susan Hammerman's description of the "International Aspects of Rehabilitation of Disabled Persons -- Policy Guidelines for the 80's." In it, she discusses the problem in a reality context and puts into clear pespective the extent to which the world can provide assurance of necessary services and support systems for disabled people. She has taken the one world apart and described for us not one or two, but went into a third and fourth world. The fourth world as I interpret her description is a part of the most advantaged nations of the world as well as the least advantaged economically and socially in the world today. This fourth world exists in all of our communities and we need not go to the third world or "developing countries" to find the suffering neglected humanity very much in need of supportive and protective services. She describes the fourth world as "composed of those groups of people within all industrial nations who still live in a condition of severe poverty: people without sufficient food, without a secure home, without social status or esteem; people whose children learn in school to be humiliated and to be confused; children who are separated from the care of their natural parents; families judged to have lower moral, ethical and work standards than others in the community. From generation to generation, the people of the "fourth world" tend to live in extreme poverty and at the bottom of the social scale. They are joined by others who are poor and culturally vulnerable such as migrant workers, new immigrants, including disadvantaged racial and ethnic groups."

I was left somewhat disillusioned in Susan Hammerman's conclusion that the vast majority of the world's 500 million physically and mentally disabled people are out of reach and out of help. However, I do keep my optimism and, perhaps, idealism, as she suggests the important directions and principles to be followed as we seek to reduce the impact of disability in our time.

I believe Mary Switzer would agree. She believed so strongly that the creative spirit of man could achieve the higher plains of personal goals and bring to reality the enjoyment of all beautiful things for all people. She also added her hope that mankind's care and concern "continue to bring even more hope to the millions to whom life means so little without hope."

• Dr. Burress is currently Executive Director of the People-to-People Committee for the Handicapped, former Rehabilitation Services Administration Commissioner for Region 8 (USA) and long-time colleague of the late Miss Switzer.

Introduction

Each year, as a living tribute to the memory of a great leader in the field of Rehabilitation, the National Rehabilitation Association, through the Mary E. Switzer Memorial Fund, sponsors a special program. These have come to be known as the "Switzer Memorial Seminars" and they explore in depth a particular topic of vital interest in the rehabilitation of handicapped individuals. Usually a limited number of persons selected for their achievements and involvement in the topic to be studied, are invited to participate and are designated as "Switzer Fellows." The outcome of each Seminar, documented in the form of a monograph, is expected to stimulate current thinking and action in the area of Rehabilitation under study at the Seminar. Recommendations for action focus on such areas as program and policy development, service delivery, research, training and legislation.

The Current Seminar

The Fifth Annual Mary E. Switzer Memorial Seminar was held in New York City from November 10 thru 12, 1980, and was hosted by the World Rehabilitation Fund, Inc., located at the Rusk Institute.

The topic of this year's Seminar was, **"International Aspects of Rehabilitation of Disabled Persons: Policy Guidance for the 1980s."** The timing of the subject coincides with the United Nation's International Year of Disabled Persons (1981). It was the desire of the Switzer Memorial Committee that the monograph of the Seminar would be ready early in 1981 to be used as a resource in the activities of the International Year as well as during the decade of the 80's.

The "Switzer Fellows" were welcomed by Howard A. Rusk, M.D., of the host organization; Brockman Schumacher, Ph.D., Chairperson of the Switzer Memorial Committee of NRA; Richard C. Englehardt, Region II Director for Rehabilitation Services Administration and Margaret J. Giannini, M.D., Director, National Institute of Handicapped Research.

In addition, a special welcome was given the participants of the Seminar by the Honorable Carl McCall, an Ambassador with the U.S. Mission to the United Nations.

Dr. James F. Garrett chaired the three days of intensive discussion which culminated in a number of recommendations and implications for action as we view the international scene in terms of rehabilitative initiatives. The Seminar did not resolve every issue and a reading of some of the comments and reviews of the participants will indicate that the action papers written for the Seminar raised additional questions and problems still left to be solved.

As we begin this International Year devoted to disabled persons worldwide, it is the hope of all of us involved in the Fifth Switzer Memorial Seminar that this monograph will be a useful resource. We would also expect that the monograph will stimulate thinking and the kind of awareness that leads to action.

Format of the Seminar and Monograph

Five "Action Papers" were prepared specifically for the Memorial Seminar by participants in this seminar. They focused on topics such as prevention of disabilities; integrating disabled persons into their society; assurance of services and support systems and information and dissemination in rehabilitation.

The action papers were sent to all designated Switzer Fellows well in advance of the actual Seminar. Reviews and comments were completed prior to the Seminar. In addition, the Action Papers were also sent to Rehabilitation and Health experts in various countries. The Seminar provided a forum to discuss these issues in depth. This was done in both plenary sessions and small work groups that focused on each "Action Paper."

The three-day program of intense deliberations culminated in a number of recommendations for action in the area of policy and program development, service delivery, research, training of personnel and legislation.

The format of this monograph closely follows that of the Seminar itself. Each Action Paper is reflected as a Chapter and included a section on "Reviews and Comments" of the Fellows and the recommendations and implications for action.

There is also a section showing the selected excerpts of responses from experts from various geographic locations around the world.

It is the hope of all persons involved in this Fifth Switzer Memorial Seminar that the chapters will provide awareness and stimulate thinking and action on behalf of handicapped persons throughout the world.

Chapter One
By Norman Acton

Institutions for Disability Prevention and Rehabilitation

Summary Comments

The paper paints an international mosaic about the extent and complexity of the service systems serving disabled people. It is a picture which is apt to "boggle the mind" of all but the most sophisticated systems theorists. Almost, without exception, cooperation world-wide, in the planning, mobilization and delivery of services, ranges from poor to inadequate or non-existent. The author concludes:

"The question, then, is to determine what institutional arrangements will, in any given political, economic and social structure, offer the maximum possibility of accomplishing the objectives implicit in (the) concepts...that a 'comprehensive and coherent response' to the problems of handicapping must address three major areas of action: prevention, rehabilitation and modification of the social field."

There is a growing recognition and understanding that adequate services to disabled people must be comprehensive, provide a range of options and have assurance of continuity. Primary and secondary consumers, and enlightened service providers, are now demanding nothing less.

There are contrasting examples of center-periphery approaches. Within the socialist world, the Chinese model of local self-help contrasts with the high central control of other socialist societies. The Swedish model alluded to in the paper is probably a compromise between the extreme of center-periphery polarization of the other systems alluded to and other examples could be cited.

This is an extremely critical area for the Seminar delegates to consider. Some resolution could emerge in answer to Acton's challenge, if the problem is approached in the most manageable form - from the community upwards.

Reviewed by G. Allan Roeher, Ph.D.

Society's response to the problems associated with physical and mental handicapping must take into account two unmistakable and inexorable trends. First, there will be a great increase in the numbers of people throughout the world who are or will be impaired, disabled and/or handicapped.[1] It is anticipated that the world's population will increase to more than six billion by the year 2000, producing by present experience and by population increase alone at least an additional 100 million disabled persons in the next 20 years. Second, there is a steadily more manifest public awareness of these problems and an accompanying burgeoning of demands for corrective action. The celebration in 1981 of the International Year of Disabled Persons, as proclaimed by the United Nations General Assembly, will have as its principal outcome the stimulation and acceleration of the second of those trends.

Predicted developments in closely relationed economic and social areas are certain to make the solution of the problems of handicapping more difficult and more complex. Two examples are:

—The Director General of the International Labour Office has estimated that "in the industrialized North around 60 million jobs will have to be created between 1980 and the end of 1987 both to absorb those joining the work force and to eliminate existing unemployment; but in the industrializing South nearly 600 million new jobs will be needed to give each member of the work force an income adequate to meet his own minimum basic needs and those of his family."[2] It is not difficult to understand the significance of those estimates so far as the employment problems of disabled persons are concerned.

—As is already being experienced, a smaller proportion of the population will be contributing to social security and tax-supported assistance systems while a larger proportion will claim the benefits. Most nations are encountering serious difficulties in financing existing systems and current numbers of clients. None has recognized the full implications of the combination of demand for expanded services and social response, predictable increases in the numbers of people to be assisted, and a proportionate decline in the population base which provides the funds for the system.

Since no nation has yet provided adequate solutions to these problems at the levels of past or present incidence, and none has realistic plans for the future, it is most appropriate at this moment to examine the readiness of society to meet the challenge. Such examinations must take place at many levels; the present paper is concerned with the development of institutions to formulate and activate the national policies which constitute society's response to handicapping.

Society's Response to Handicapping

An acceptable response by society to the problems under consideration must address three major areas of action:

--It must seek to prevent as many as possible of the impairments which lead to disability and handicap.

--When impairment has occurred, it must seek to prevent the consequence of permanent disability or, if that is impossible, to enable the individual concerned to perform the essential functions of life despite the limitations that may be present.

--It must reduce or eliminate the handicapping that results when a combination of impairment or disability and the nature of the social field in which the individual operates limits the fulfillment of expected life roles.

Historically, the response of society to the "problem of handicapping" has been concentrated on the delivery of services that attempt to correct, minimize or compensate for the impairment so that there will be minimal functional limitations. It has also sought to create special conditions of living and work to accommodate the limitations of disabled persons. The broad areas of public action needed to prevent impairments, which are caused primarily by inadequate nutrition, faulty practices surrounding birth, diseases, infections and accidents, have not, for the most part, been included in the policy context or in the responsibilities of institutions designed to deal with handicapping. Only recently have such policies and institutions begun to address the tasks of modifying the social field so that the full participation of persons with disabilities is both facilitated and welcomed.

Mankind is not in any significant way reducing the incidence of disability in the world, and is progressing all too slowly in opening society to those who are different because of physical or mental characteristics. An examination of the validity of policies and institutions must take these realities into account. The interlocking relationships among the conditions named (impairment, disability and handicap) suggest that an effective attack on the problem must encompass a continuum of prevention, rehabilitation and enlightened social policy. Individual institutions may specialize in segments of the whole, but a national response addressed to the totality of the problem must be designed to activate the entire continuum, and it must have the capablility of assuring the coherent articulation of the component parts.

The Institutional Framework

The policies, the institutions and the patterns of services to be found in the various nations are, of course, products of their histories and of the economic, social and political systems with which they operate. What exists has rarely been designed by a rational process, taking into account all relevant information and based on an understanding of the real nature of the total problem. Most often, proponents of rehabilitation programs have found it necessary to practice the political "art of the possible." This has very often led to the establishment of programs and institutions whose formal objectives have been centered on a segment of the problem, such as vocational rehabilitation, research, or elimination of physical barriers, which was found to be understandable to legislators and responsive to popular concerns. Employed skillfully, some of these programs have served much broader objectives, but the circumstances behind them make it clear that a rational and comprehensive approach to the full dimensions of the problem is not easily mounted or merchandized. The institutions that have emerged to implement such programs usually reflect in their nature the ambivilance of the situation -- a formal compliance with stated and limited purposes, a practical orchestration of more extensive functions. While often managed with brilliance, they do not provide institutional models upon which to build.

The rational and comprehensive approach is both desired and sought. The First Rehabilitation International Conference on Legislation Concerning the Disabled, held in Rome in 1971, brought together many of the individuals responsible for the administraton of national rehabilitation institutions. They fully agreed on the following statement in the conclusions of the Conference:

"Recognizing that successful rehabilitation services encompass education, medical and para-medical care, social assistance and vocational training and guidance, and that several ministries or equivalent agencies of government should be assigned parts of the work, the Conference urged that constant attention be given to the coordination of planning, budgeting, financing and administering of the respective programs. It strongly recommended the creation for this purpose of inter-ministerial coordinating groups at decision making levels."

Seven years later, many of the same people were joined by senior officials from a number of developing countries at the Second Rehabilitation International Conference on Legislation Concerning the Disabled in Manila. "The Manila Statement" adopted by that meeting includes the following recommendation:

"A national council for the welfare and rehabilitation of the disabled should be established by legislation in each developing country.

a. Such a council should consist of representatives from:

1) Major government departments concerned with all aspects of rehabilitation.

2) Voluntary agencies; and

3) Organizations of persons with disabilities.

b. Such councils should be charged, inter-alia, with the following functions:

1) Identifying basic needs of the disabled and any inequalities and discriminatory practices affecting disabled persons in their countries.

2)Producing a rehabilitation plan in which priorities are established, respective roles and responsibilities of the government and private sectors are defined, and adequate methods are provided to ensure a coordination of the total effort for the rehabilitation and welfare of disabled persons.

3)Advising the government on all aspects of welfare and rehabilitation of disabled persons.

4) Continuing evaluation of the effectiveness, based on cost benefits and other criteria and of other values of services provided.

It will be noted that these formulations deal primarily with the delivery of rehabilitation services (although it should be conceded that, in the minds of some of the drafters, the terms "rehabilitation" and "welfare" had slightly wider connotations). There is no mention of prevention and the issues associated with the quality of the social field are recognized only as "inequalities and discriminatory practices."

During the years 1978 and 1980, Rehabilitation International engaged in the most extensive international consultation ever devoted to policy concerning disability prevention and rehabilitation. This process, which included participation by regional R.I. conferences and world meetings of other, related organizations, was used to draft the text of a Charter for the 80s to be given consideration by the participants in the 14th World Rehabilitation Congress at Winnipeg in June, 1980. Throughout the world, wide agreement was found as to the importance of including the full spectrum of prevention, rehabilitation and enlightened social action in the text of the Charter. As to national institutional arrangements, the draft text presented in Winnipeg included the following:

"Each country is urged to prepare a comprehensive national plan for the achievement of these aims in the light of the principles enunciated in this Charter and of its own circumstances. The plan should involve all major sectors of national life and be a component of high priority in any programs for national development.

"For these purposes it is essential that each country should have within its government a minister for the disabled, or person of equivalent rank, directly responsible to the Head of State or Government, as is appropriate, to direct the preparation of the national plan and to coordinate its implementation. This coordinator should be assisted by a national advisory body including representatives of all relevant government departments, organizations of the disabled, and voluntary and professional groups."

When the text was discussed by some 200 round table groups at the World Congress, there was general agreement with all of the above concepts except that of a minister for the disabled. The principal reason given for opposing the appointment of a minister, or for reservations about that concept were:

--That the objective should be to have necessary services for prevention and rehabilitation incorporated in the responsibilities and functions of each relevant department or agency, with a general coordinating mechanism but without giving the lead role to any individual or institution.

--That the designation of a minister risks leading to separate and separated services which will deter integration of disabled persons in society.

As will be seen in the discussion below of the situation in a country with a minister for the disabled, the above issues are, in part at least, a result of different word usages and of different understandings of the functional implications of the post of minister.

No systematic study of the institutional structures being used in the various nations has been carried out, and no comparative analyses of such structures and their relationships to economic, social or political systems are known to exist. In most cases literature purporting to describe national programs covers only segments and does not identify the **de facto** situation. Better information and analysis is badly needed, especially by countries in the process of initiating or expanding national programs. Until it is available, however, descriptive material and subjective evaluations must be drawn upon.

Observations suggest that the institutional frameworks through which most countries' activities related to handicapping are carried out are composed of one or more of the arrangements listed below. Frequently, more than one of them is being employed in a given nation and, very often, the **de jure** situation is based upon one of them or one combination while the **de facto** situation is using a different arrangement. One or more of the following may usually be found:

--An inter-ministerial committee or coordinating group.

--Several ministeries or departments contributing to what is described as a coordinated program with one of them having a lead responsibility.

--A national council which includes not only the relevant ministeries, but also representatives of other entities such as voluntary and professional organizations, groupings of disabled persons or their representatives, trade unions, employers and others.

--A multi-agency system in which each performs some functions related to disabled persons with varying degrees of coordination and communication among them.

--A minister for the disabled or other senior personality charged with some degree of responsiblity for initiating, stimulating, implementing, and obtaining support for a national effort.

--A more or less extensive reliance on services provided by voluntary organizations working with or without material support from the government, and with varying degrees of cooperation and coordination.

Criteria for Evaluation

As has been noted, practitioners from countries in which each of the above arrangements is employed alone or in combination with others, when gathered in international assembly, unfailingly endorse the principle of coordination. They usually favor an inter-ministerial committee, national council or other institution as the instrument of coordination. In recent years, attention has been given to the idea of having a minister or other senior personality as a catalyst of coordination. There has not been, however, a systematic and comparative examination of the experiences upon which their recommendations are based.

Such an examination would produce findings of great value to all nations. It should seek to understand not only the functional experience so far as service delivery is concerned, but also the links, if any, between the types of institutional framework and the national policy, or lack of it, in response to handicapping. Such considerations as the following should be injected into the inquiry:

Is there a comprehensive and coherent national policy which includes prevention of impairment, rehabilitation of the disabled, and action to eliminate physical and social barriers to the participation in the community of people with disabilities? Since no country is known to have such a policy, it would be important in each case to determine whether the existing institutional framework can generate the necessary political decisions; or whether it will manifest the inertia described by Milovan Djilas -- "Any system claiming to embody a substantial social entity will gravitate inexorably toward consolidation, and the elimination or exclusion of change."[3]

Would the existing institutional framework be capable of managing the coordination of the great variety of actions needed to bring alive the entire continuum of response described earlier? This includes the limited question of delivering coordinated and integrated rehabilitation services in the larger context of a total national response to handicapping.

Is the institutional framework capable and sufficient to activate the national policy for the entire population -- for the poverty-stricken, for those in remote areas, for minority groups, for the increasing numbers to be expected in most countries?

A response to the total problem of impairment, disability and handicap requires the understanding and participation of each community in the society in a process of changing both attitudes and behavior. Does the institutional framework encourage and facilitate a sufficiently broad base of involvement?

Closely related is the issue of centralization versus decentralization of responsibilities, services and activities. Trends in both directions may be found in the world, some applied horizontally in the upper echelons of government and others vertically down to the role of the local communities.

Another dimension has been added with the belated recognitiion of the roles disabled persons and their organizations and representatives can and must play in a system. Few existing institutions are structured to accept this element in a natural and responsive manner, and many find it difficult to define and accomplish the necessary adjustments.

Finally, there is the difficult problem of trying to apply some measure of relative cost effectiveness to the different institutional systems. Since it has not yet been learned how to value all of the costs and benefits involved in the process of providing rehabilitation services for an individual, especially those of a psycho-social nature, the difficulties of compiling any statistical measurements of the totality of a nation's handicapping situation are substantial. In governments, consolidations and centralizations are usually represented as producing more economical administration of programs, but Mr. Parkinson's Law often disurbs the apparent logic in that formula. When, as is suggested by the criteria listed above, the universe of action under consideration includes the attitudes and behaviours of the entire population, of the institutions and communities in which it is structured, the economy of national administration becomes only one of many factors, most of which are difficult to quantify. Nevertheless, the alternatives must be viewed from the perspective of cost as related to results -- if only to make the chosen solution more palatable.

Some Case Sketches

Understanding of the issues being considered will benefit from descriptions of some national situations which typify the relationships among policy generation, institutional machinery, and service delivery including social action.

The **United States** undoubtedly has as much handicap policy as any nation in the world. In keeping with its history and traditions, it has proportionately as many institutions at every level of the governmental and private sectors to deal with the problems of handicapping as any other country. Its expenditures, estimated to have been $83.1 billion in 1973 for direct services and disability-related income maintenance,[4] are significant. Responsive to trends, it has an

agency, office, institute or committee for every facet of the problem that has come into prominence. As is true of many countries, the U.S. Government, the state governments and many county and city governments have **de jure** institutions and systems for the coordination of all this, but the reality often follows other paths.

The complications of the U.S. "system" are perhaps most apparent to the individuals who become disabled, or their families, as they try to find their way to needed services and support systems. Nearly the same level of puzzlement is experienced by observers from other countries who, like the blind men describing the elephant, are inclined to understand the American approach as being whatever area of service they may have encountered. Many U.S. institutions can and do give valuable advice, examples and training for other countries developing certain specific service programs, but it would be an unfortunate nation that set out to model its national institutional framework on what it found in the United States.

The U.S. pattern, while excelling in many details, is, mainly because of the multiplicity of programs and agencies, inefficient, overly expensive and slow to respond to evolving concepts of the problem in its full dimensions. Could these flaws be corrected by a different institutional structure? For example, a Secretary for the Disabled, an inter-departmental committee with leadership empowered to enforce coordination? To contemplate the amount of legislation needed for such a change, the number of interest groups to be influenced, the modifications in Federal-State arrangements, etc., makes it difficult to think about alternatives even in the most theoretical exercise. But, if one could imagine the possiblity of such changes, it would remain an open question whether community involvement would be affected for better or worse, whether a more centralized bureaucracy would, as they often do, become less responsive to evolving understandings of needs and opportunities.

And, perhaps the most important question of all, can a more comprehensive and coherent institutional structure be devised unless and until agreement has been reached on a comprehensive and coherent national policy responsive to the entire problem of impairment, disability and handicap? The beginning of the slow evolution of an American policy towards this issue has been placed in 1911. Could its pacing and its conceptualization be improved by the creation of a different institutional framework, given the responsibility and the authority to move ahead? The only answer to be given to those questions is that it is unlikely to happen.

In 1974, the Labour Government in the **United Kingdom** named the world's first Minister for the Disabled, the Rt. Hon. Alfred Morris, M.P. This step was welcomed in Britain and in many other countries as evidence of a new level of recognition for the problems of people with disabilities. Moreover, as Mr. Morris undertook his assignment with energy and dedication, a belief gathered international currency that this institutional arrangement offered new possiblities of policy development, coordinated action, and efficient administration. Hence, many contributors to the drafting of the Rehabilitation International Charter for the 80s were eager to include the recommendation that every country should have a Minister for the Disabled or the equivalent.

It denigrates neither the importance of the Labour Government's initiative nor the achievements of Mr. Morris as Minister to point out certain factors that may limit the exportability of this experience in its pure form. The history of the matter was that Alfred Morris, as a Member of Parliament, was the instrument for the introduction in 1970 of the Chronically Sick and Disabled Persons Act. Substantial legislation already existed in Britain and, in particular, the National Health Service and the Department of Employment (now renamed the Department of Manpower Services) had extensive programs dealing with elements of the services needed by disabled persons. The new Act, the first concerned solely with disability, amended 39 other Acts of Parliament and sought to cover the entire field, including new areas of case finding, social assistance and community respon siblity. It continued the British tradition of relying heavily on voluntary organizations, of which there are many spread throughout the land, for social services. Some refer to the Chronically Sick and Disabled Persons Act as the Magna Carta of Britain's disabled; others believe that it falls short in coverage and in implementation of constituting a complete national policy. In any case, however, when Mr. Morris was appointed Minister for the Disabled, he, as the M.P. who had introduced the legislation, approached its implementation with a special dedication and zest.

The British Minister for the Disabled is a junior minister in the Department of Health and Social Security. There is no "Department" or "Ministry" for the Disabled, and services continue to be provided by the Departments of Education, Manpower Services, Health and Social Security including the National Health Service, and other organs of government as well as voluntary agencies. The Minister for the Disabled is charged with promoting inter-departmental coordination and with taking an overview of the totality of the problem. These are both useful functions, especially when performed with Mr. Morris' zeal, but it must be understood that he had no power of coordination and, while it is reported that communications among the departments improved during his term, it is not certain any significant change took place at the level of performance.

Remaining, as is the case in the British parliamentary system, an M.P. while he served as Minister, Mr. Morris was able to secure the adoption of additional legislation and appropriations to carry forward the intent of the original Act. He was, of course, supported in this by the Labour Government and by a Minister of Health and Social Security who was especially interested and effective. In addition, however, Mr. Morris created for himself a role akin to that of an ombudsman. Traveling a great deal, he encouraged individual disabled persons and groups to bring their complaints and problems to him and mail of this type arrived in large quantities at the Elephant and Castle where his staff was

based. Although he had no responsibility for the service functions of any of the departments, Mr. Morris and his staff did what they could to get satisfaction for those who brought their problems to him.

The point of this very inadequate description of the situation in the United Kingdom is not to pass judgment on either the Chronically Sick and Disabled Persons Act or Mr. Morris' service as Minister, but to make the point that there were in his appointment and in his achievements a series of circumstances which were unique to the British system and to this particular experience. It would be rash to assume that the appointment of a minister for the disabled or equivalent in other systems would necessarily have the same impact or results.

Sweden provides several kinds of examples of decentralization of the institutions working in the field. These trends are especially interesting when viewed in the context of the country's long history of planning on the basis of national government responsiblities for the welfare (in the broad meaning of the term) of all its citizens. This philosophy of government, when combined with the facts of a relatively small and homogeneous population and many years of affluence, has led to institutional structures that are neither typical nor easily transferable. It is, however, important to recognize that another product of the Swedish experience has been the capability to gather more extensive and reliable data about the characteristics and problems of the people than has been possible for most nations. Working with such data and with the other characteristics mentioned, the leaders and the people have shown an unusual readiness to innovate and experiment in programs affecting the well-being of the population. These considerations have all influenced the development of both institutions and services for disabled persons.

Of particular relevance to the present study are some current explorations of decentralized formats for the institutions dealing with services for disabled persons and the social and environmental factors involved. They are:

--The transfer of responsibility for health and welfare services to County Councils, which are the smallest government unit with facilities for these purposes. Thus, prevention, case finding, rehabilitation and social action are coordinated at that level with policy guidance and technical assistantce from central authorities.

--Experiments by the National Labour Market Board, which in the past had a highly centralized role in dealing with the employment problems of all disabled persons, to create situations in which the employment of disabled persons will be facilitated by in-house "adjustment groups" and other measures less dependent than in the past on the central authority.

--The allocation to organizations of and representing disabled persons of functions formerly performed by governmental and private institutions. The government subsidizes these organizations. Their emphasis is primarily on public education and awareness projects, monitoring facilities and services, and filling advisory roles in planning organs. Recent reports indicate that national institutions which previously carried out some of these functions are faced with sharply reduced responsibilities and considering modifications in their structures and programs.

In both the **Federal Republic of Germany** and **Japan** tendencies towards the centralization of services in centers and programs operated by governmental institutions appear likely to affect the roles and functions of traditional institutions. A full understanding of the implications for the overall structure of the societies' response requires more detailed study and observation than has been possible.

Brazil provides an interesting example of the situation, which exists in many other countries, in which one or several ministries or other agencies have developed programs with little or no reference to others working in the same or closely related fields. The Ministry of Health supports a major rehabilitation facility in Brazilia, the Capitol, and several other lesser centers; the Ministry of Social Security, through the Instituto Nacional de Prevencia Social [INPS], operates the largest network of services and centers; the Ministry of Education has a national training center for teachers of special education and gives assistance to the states, which operate the schools; the Ministry of Labor appears to have little or no concern with disability problems; some rehabilitation centers and facilities are operated by universities, university-related hospitals and voluntary organizations. The Ministries of Social Security and Education have published joint policies relative to their programs for exceptional children, which are implemented to some degree through three semi-voluntary bodies subsidized by these ministries. This appears to be the only instance of real collaboration between the various agencies.

In an effort to improve the situation, the Government of Brazil has recently established a committee to suggest new patterns for legislation and the institutions necessary to mount a more comprehensive national coverage. The effort to locate models that could be separated from the particular political and historical contexts in which they have evolved to a degree sufficient to be of help to the Brazilians has highlighted the need for better information and analysis of institutional frameworks.

The situation in Brazil is replicated with minor variations in many other countries, especially in Latin America where the Social Security institutions are frequently the best financed and hence the most prominent rehabilitation facilities.

The above inadequate sketches of parts of the situations in some countries are presented with reluctance to convey some idea of the issues to which the theoretical sections of this paper refer. It must be emphasized that the information given does not do justice to the value of the actions being taken in these countries, nor does it describe adequately the gaps between what was referred to earlier as a "comprehensive and coherent response to the problems of handicapping" and the **de facto** situation in these other countries. To overcome those faults would require a great deal more

research than has been possible for the preparation of this document.

Conclusion

There is a lack of systematic and reliable information about the institutional framework of the national response to the problems of handicapping in any country. Much descriptive material may be found dealing with the organizations and methods for delivering the various rehabilitation services and, to a lesser extent, for seeking to modify the social field. Programs to accomplish the objectives needed for prevention of impairment (e.g. mother and child nutrition, counselling and guidance of parents, improved maternal and child health services, immunization, better care of those affected by disease and infection, accident prevention in the home, at work, on the highways and elsewhere) are, when they exist, usually found in other institutional areas than those concerned with disability. Actions to influence some of the more general factors leading to impairment and disability, such as poverty, war and civil strife, fall within institutional areas where the political overtones require completely different avenues of approach, which are not dealt with here.

It is suggested that each nation should approach the problems of handicapping in a manner that will evolve a "comprehensive and coherent response" incorporating suitable planning and effective implementation. Three considerations are believed to be essential:

--First, the response should address three major areas of action: prevention, rehabilitation and modification of the social field.

--Second, those three areas of action should be regarded as a continuum of interrelated functions rather than as separate tasks.

--Third, the response to handicapping should be included in the designs for action for more general economic and social development. This is of particular importance in the developing countries where the "national development plan" is a key instrument of priority-setting and of budgeting.

The question, then, is to determine what institutional arrangement will, in any given political, economic and social structure, offer the maximum possibility of accomplishing the objectives implicit in those concepts.

International gatherings are quick to recommend, as was quoted earlier from The Manila Statement adopted by the Second International Conference on Legislation Concerning the Disabled, that there should be a "national plan" and that it should be prepared and implemented by a "national coordinating committee." Some countries have followed that procedure with more limited objectives than those described above. More often, the national plan has been prepared by existing institutions, executive or parliamentary or both, and out of it has emerged a new insitutitional framework. No basis exists to evaluate the relative merits of these approaches, and it is entirely possible that all of them, and others, are equally efficacious when they are in harmony with the paticular circumstances in which they are employed.

The development of a national policy that will address all aspects of the intertwined problems of impairment, disability and handicapping, and the creation of an institutional framework that is effective in implementing all facets of that policy, must be the objective in every nation. If the exchange of experience in seeking those goals is to be of real value, if the advice and examples to be offered to countries which are beginning their response in this field are to be useful, it will be necessary to examine these issues and the related experience much more fully and scientifically. Realistic analyses should be made of the **de jure** and **de facto** institutional arrangements in a number of countries that are typical of the different economic, political and cultural situations to be found in the world. The information gained should be subjected to comparative analysis with the objective of identifying the factors that are critical for successful institution building. The findings of such studies would be of great value to all countries as a backdrop against which to reexamine exisiting institutional arrangements, and of special value to newly developing countries where the processes of planning and program implementation are in their early stages and the institutional framework for a national response to handicapping has not yet become rigid.

Footnotes

1. In this paper, the following terms have been used with the definitions indicated:
   Impairment -- "Any loss or abnormality of psychological, physiological, or anatomical structure or function."*
   Disability -- "Any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being."*
   Handicap -- "A disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual."*
   Institution -- An organizational system.
2. **Medium Term Plan of the ILO for 1982-87,** International Labour Office, Geneva 1980.
3. M. Djilas, "Yugoslavia and the Expansionism of the Soviet State," **Foreign Affairs,** New York, Spring, 1980, p. 852.

* *From International Classification of Impairments, Disabilities and Handicaps, World Health Organization, Geneva, 1980.*

4. S.Z. Nagi, "The Concept and Measurement of Disability," **Disability Policies and Government Programs**, E.D. Berkowitz, Ed., Praeger, New York, 1979, p. 1.

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Excerpts of Reviews and Comments

The following are excerpts of reviews, comments and questions raised by the Switzer Fellows. These are presented to further stimulate thinking as well as action as it relates to the content of the chapter by Norman Acton.

"When one confronts the 'cross-cutting' nature of rehabilitation, that is, its application to all phases of the disabled person's life with the categorical, specialized and segmented organizations of the rehabilitation industry - particularly in the United States - it's clear to see why we must continue to focus upon service coordination. While we all may endorse the principle of coordination, the question remains - who is to fashion the coordination, who is to take the lead responsibility to see that the complex interdisciplinary and interorganizational service system responds to the individual's needs. Is it realistic to expect the person with the disability to weave his/her way through the maze? Is it the primary responsibility of consumer organizations? State rehabilitation agencies? Voluntary agencies?

The author should address the question of the 'tranferability' of institutional structures given the unique political, social, and economic situations in each country. For example, in terms of superordinate governmental policy and structural arrangements, can we assume that the approach of the social democracies (Sweden, W. Germany or England) would be given serious consideration in the United States? Also, has the author confronted such nationalistic resistance among various countries; if so are there any effective approaches he would suggest to overcome the official or popular conception that 'things are so different here that we have little to learn from others who do not share our social, politcial or economic values?' "

--Donald E. Galvin, Ph.D.

"Mr. Acton's impressive paper stresses the importance of each nation's having a national policy which will address all aspects of education and rehabilitation of the handicapped and will place emphasis upon prevention of impairments. While international conferences on rehabilitation have been pleased to list recommendations, possible procedures for carrying them out are not clearly understood. Mr. Acton suggests the need for a systematic study of institutional structures of various nations and their relations to economic, social and political systems as one means of judging application of procedures for initiating or expanding national programs."

--Jeanne R. Kenmore, Ph.D.

"The author touches upon one of the most difficult, if not the most difficult problem, faced by the field of international rehabilitation. The problem is to establish institutions for service delivery which are germane to the character of involved nations and which have proved to be efficient and effective in meeting the needs of disabled for the coming years. It will be most helpful for the Seminar to explore in greater detail the current evidence about which institutional arangements have been effective or ineffective. The examples used by Mr. Acton support the view that each nation is different and is in need of its own arrangement. If current information about the adequacy of health delivery institutional arrangements is unavailable, the Seminar should propose that this matter be studied by an appropriate agency. The purpose of the study is to determine the current institutional arrangements and make some judgments about their efficacy in meeting the needs for good health care. Following the study, a model should be developed which assists nations in building their own institutional arrangement suitable for their history, culture and national character.

Though there is some degree of success with better health delivery at the community level, the question remains about the future of such an approach without the support and direction of central government. It would be interesting to learn of examples of communty level health care projects which have had a multiplier effect throughout their country. Many of the projects cited in the literature have not had a catalytic effect to the extent expected."

--Michael Marge, Ed.D.

"The author dissects the problems associated with physical and mental handicapping conditions exceedingly well in this paper. His international case approach, however, should have included countries from Africa, Asia, Central America, the West Indies, and the Middle East. Problems of Institutions for Disability Prevention and Rehabilitation are observed in these areas of our world. We are in complete agreement with his conclusions and recommendation as to programs needed to accomplish objectives."

--James S. Peters, II, Ph.D.

"Acton outlines national institutional arrangements to coordinate and mobilize disability prevention and rehabilitation efforts suggested by rehabilitation planners and practioners from various countries. But the concept of centralization of rehabilitation efforts runs counter to the current movements towards decentralization of human services delivery systems in many developing countries."

--Robert B. Ransom

"Uniform national policies regarding disability is a worthy international goal. Given the wide variances in political systems, resources, religions, and individual national problems, it may be an elusive goal, or as serious, it may be only a paper victory if such a policy is established. We are all familiar with the abuses to which the United Nation's Declaration of Human Rights has been subjected. The International Year of the Child was violated in parts of the world by mass starvation and slaughter of children. International policies can produce, or be perceived as producing, the opposite of their intentions.

Inherent in both the Acton paper and the Curtis paper is a criticism of centralization and its attendant professionalism. Sweden, which set the tone for many developed nations in their approaches to disability, seems to once again be ahead of the crowd in decentralizing and allowing decisions to be made by disabled people, i.e., from small, local groups of people most directly affected, those with disabilities. The U.S. experiment with 'centers for independent living' seems to be following this direction."

--Robert H. Ruffner

Summary of Recommendations

The following is a brief summary of recommendations and implications for action as developed by the Switzer Fellows as it relates to the topic of the first chapter. (The recorder was Martin McCavitt, Ed.D.)

The working group discussed the paper at some length and closely examined the authors recommendations. The working group had the advantage of having before it the preliminary draft of the Declaration of the Rehabilitation International Charter for the 80s, which is a comprehensive and well-developed thesis of where we go from here for the next ten years. It was developed by a very astute and well-informed group of specialists, assisted by the results of consultations held in many parts of the world.

In the Charter, each country is urged to prepare a comprehensive national plan for the achievement of long-range goals in the light of the principles it enunciates. The plan should involve all major sectors of national life and be a component of high priority in any program for national development; it should provide for the full participation of people with disabilities in such programs, including all sectors of national and community life!

It is stated that, "the Charter for the 80s is a statement of consensus about measures to enable humanity to protect and nourish the rights and responsibilities of every person, those who are called disabled and those who are not."

The Working Group made several recommendations based on its discussion of the paper. While recognizing the theoretical objective of a comprehensive national plan for each nation, the group did not believe that the preparation of such a plan was necessarily the first step of highest priority for each government. Its recommendations evolve from that pattern of thought.

1. Proper timing is essential in developing political support and consensus for program for disability prevention and rehabilitation, and it is possible to draw upon accumulating experience to evolve a national plan rather than drafting it all at once. The advent of the International Year of the Disabled Persons in 1981 will no doubt create a climate in which progress can be accelerated.

2. Comprehensive and Continuity -- Every plan should be concerned with prevention of disabilities at all levels, and the rehabilitation approach should be comprehensive in nature which means that all factors should be considered including: the physical, social, economic and psychological aspects of the person and his community. The plan should also have continuity assuring an on-going effort as well as a follow-through of all goals and objectives.

3. The stages of development both of services for disability prevention and rehabilitation and of public understanding and political support for such services varies greatly in the different regions of the world. Pressure for the development of programs and overall national plans must, to be effective, take the particular situation of the region, and of the individual country, into account. The availability or lack of resources is a primary consideration if plans are to become operative. Regional institutions can assist in developments and each national should be aware of its role in regional cooperation.

4. Study and Evaluation of the Plan -- Every effort should be made to study and evaluate the policy and planning as it is developed. Procedures for this should be an integral part of any program or plan.

5. Implementation of Program -- The greatest concern of all those who plan must be interested in the end results --that of implementation of the plan, to assure that program and services are activated and put to use for the disabled population, as intended.

Chapter Two
By Michael Marge, Ed.D.

The Prevention Of Human Disabilities: Policies & Practices for the 80s

Summary Comments

This paper is a comprehensive statement on prevention of human disabilities and recommended policies and practices for the 1980s. It is concerned with the huge problems of health and preventive measures that have been known for many years. The historical approach dating back to Hippocrates during the Fourth Century, B.C., is interesting and significant and presents a challenge for the future as we move from that point in history through the 1900s, where the leading causes of death have been influenza, pneumonia, diphtheria, tuberculosis, and gastro-intestinal infections, to the present day killers and chronic diseases commonly referred to as the big three (cancer, heart disease and stroke).

The author speaks of several public health revolutions. He believes the first public health revolution has successfully run its course, at least in the U.S. and the major industrial nations. He states that the second public health revolution is now needed in the U.S. for the prevention of the major chronic diseases, rather than the treatment of these diseases after they have developed to an advanced stage. It is pointed out dramatically that currently only a small amount of the federal health dollars are specifically identified for preventive-related activities.

The author discusses primary prevention as the inhibition or elimination of disease, injury and disability before these conditions affect the individual.

Secondly, prevention refers to the early detection and treatment of disease, and tertiary prevention is the reduction of disability by attempting to restore effective functioning.

The authors points out some general cautions in dealing with prevention and stresses five types of human disabilities, communicative disorders and social problems. He does a commendable job in describing these disabilities, but the area of greatest concern relates to social problems including alcohol and drug misuses; adolescent pregnancy; sexually transmissible diseases; and crime.

Reviewed by Martin E. McCavitt, Ed.D.

Introduction

The study and application of preventive measures to reduce disease and physical and mental suffering is not of recent origin. In fact, the interest in prevention has long historical roots as far back as Hippocrates, the imaginative and progressive Greek physician in the Fourth Century B.C. Hippocrates taught that the physician should study the whole person and not just the disease and that it is more important to **prevent** a patient's illness than to cure him.

It was not until the development of the fields of epidemiology and preventive medicine in the 19th Century, did the practice of prevention have a decided impact on disease and disability in the U.S. population. Writing about the history of preventive medicine in the United States, George Rosen observes that noticeable gains were realized during the early years of the 1900s when concern about all health problems were expressed by medical leaders and organizations (Rosen, 1975). Malnutrition and its effect on physical development was publicized. Also, awareness of dental disease as a health problem of children and adults was already present in the early years of the century. In 1900, the National Dental Association (now the American Dental Association) established a Committee on Oral Hygiene in Our Public Schools for the purpose of teaching "Good teeth, good health" to school children.

In the 1979 Surgeon General's Report on Health Promotion and Disease Prevention, it is observed that our Nation's first public health revolution was the struggle against infectious diseases which spanned the late 19th Century and the first half of the 20th Century. In 1900, the leading causes of death were influenza, pneumonia, diphtheria, tuberculosis, and gastro-intestinal infections. In that year the death rate from these major acute diseases was 580 for every 100,000 people. Today the mortality rate from these diseases is about 30 people per 100,000.

Also, increases in life expectancy and declines in infant mortality have realized notable progress since 1900. According to the Surgeon General's Report (1979) the progress was achieved by improved treatment and curative medicine and by the application of preventive and health promotion measures. Among the measures cited are improved sanitation, better nutrition, the pasteurization of milk, and the control of infectious diseases through the development of effective vaccines and mass immunization.

As early as 1951, the World Health Organization lauded these gains made by modern medicine in the following statement: "Modern public health has been developed during the last hundred years from primarily a legislative and police function to an applied science, which constitutes an important and integral part of social and economic evolution. The techniques used in health administration have consequently been changed to emphasize positive measures in planning and organizing modern health services on a community basis, in order to create a healthy environment for the people, and in educating the public for active participation in health work." (Rosen, 1975)

Now it is felt that the first public health revolution has "successfully run its course, at least in the U.S. and the major industrial nations." (Surgeon General's Report, 1979). There is a call for a second public health revolution in the United States -- the prevention of the major chronic diseases (e.g. heart disease, cancer and stroke), rather than the treatment of these diseases after they have developed to an advanced stage. The Report continues, "It is clear that improvement in the health status of our citizens will not be made predominantly through the treatment of disease but rather through its prevention." (p. 9). Despite this recognition of the importance of prevention, currently only four per cent of the Federal health dollar is specifically identified for prevention related activities.

There are many compelling reasons for increasing our focus on prevention at this time. Many Americans are deeply interested in achieving and maintaining good health status. There is a great deal of knowledge about the causes and risk factors for chronic diseases. The United States certainly does possess the resources to mount national, state and community programs of prevention. Also, all thoughtful health service professionals are aware that prevention saves lives, improves the quality of life and is cost effective in an era of health cost inflation. In view of these reasons, one must ask why prevention is not the major priority of our health care system. Part of the answer is historical and part is economic.

Currently, health care in the U.S. is provided by a diversity of professionals and agencies. Note Chart I which outlines the Spectrum of Health Care Delivery (DHEW, 1975). There is little formal cooperation among the various providers which results in serious gaps in meeting overall health care needs. For example, the U.S. system gives high priority to acute care but places limited emphasis on preventive and continuing care. If an individual is struck by a catastrophic disease or accident, the wonders of our medical technology and practice is dramatically demonstrated--at considerable cost to the patient. It is unusual and the exception, however, to find health care providers assisting an individual in effective primary prevention.

The delivery of health care in the United States operates on a monopolistic basis. The physician, not the health consumer, determines health care priorities and costs of health care. These factors lead to an emphasis on primary and acute care because that is where the money is to be made. The area of prevention is not highly remunerative. Also, educating people about good health habits and taking measures to prevent illness are complex and time-consuming activities. They have no glamour for health care providers in a system geared to sophisticated medical technology and practice. Private doctors and neighborhood health centers provide some preventive care by administering innoculations to patients and testing them to determine potential health problems. But the education of patients about good health habits is generally overlooked (DHEW, 1975).

The complexities and difficulties in instituting a community-based program in prevention are overwhelming to many individual health care providers. "Where do you begin?" is a question often asked by health care providers unfamiliar with the area of community based prevention programs.

Preventive care, therefore, is considered the weakest aspect of our health care system in the United States (DHEW, 1975). In theory and practice, prevention should be incorporated as a systematic part of health care delivery at every level. Unfortunately, this is only found in several health maintenance organization (HMO)-type arrangements such as Kaiser Permanente and the Harvard Community Health Plan.

Definition of Prevention

When considering an operational definition of prevention, it is important to focus on the ultimate purpose of a prevention program: the elimination of disease and disability and the maintenance of health. Health is a difficult concept to describe and measure. One of the most widely cited definitions of health is found in the Constitution of the World Health Organization:

"Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." (1948).

Diseases should be perceived as entities which have a natural life history, extending over time through a sequence of stages (Mausner and Bahn, 1974). It is now known that factors leading to the development of chronic diseases often are present in early life, many years before the appearance of clinical disease. The sequence of states in the history of disease are described as follows (Mausner and Bahn, 1974):

1. State of susceptibility: At this stage the disease has not developed but the "groundwork has been laid" by the presence of factors which favor its occurence. For example, heavy cigarette smoking increases the prospect of coronary heart disease and lung cancer.

2. State of presymptomatic disease: There is no obvious disease but undiagnosed changes have started to occur. For example, premalignant alterations in tissue are taking place.

3.Stage of clinical disease: The occurance of obvious anatomic or functional changes is diagnosed with recognizable signs or symptoms of disease. For example, the detection of cirrhosis of the liver after many years of alcoholism.

4. Stage of disability: According to the nature and severity of certain diseases, some run their course and are resolved spontaneously or as the result of medical intervention. Others may lead to a residual problem and a short term or long term disability. For example, a child with a moderate hearing loss resulting from repeated bouts with otitis media may experience total recovery after a program of medical intervention. But individuals who suffer spinal cord injuries often experience some degree of disability in physical functioning.

Disability can be defined in various ways. In community surveys it usually means any limitation of a person's activities to include the following: the individual's psychosocial role as a family member, student, wage earner or homemaker. It is the loss of function rather than the structural defect which is of greater significance to the rehabilitation specialist. Since individuals differ in their response to disease and physical defects, their resultant level of disability will differ.

It was mentioned above that disease follows a natural course of development over a period of time. As disease evolves over time, pathologic changes may become fixed and possibly irreversible. The major goal, therefore, is to push back the level of detection and medical intervention to the "precursors and risk factors of the disease." (Mausner and Bahn, 1974). Simply stated, prevention is the inhibition of the development of a disease before it occurs. But in recognition of the natural history of disease, a broader definition is necessary and will be more relevant. Three levels of prevention are recognized (Mausner and Bahn, 1974).

Primary Prevention is the inhibition of the development of a disease by altering susceptibility or reducing exposure for susceptible individuals. It is generally achieved through two major categories of activities: general health promotion and specific health measures (e.g. immunization, environmental sanitation, and protection against accidents and occupational hazards).

Secondary Prevention is the early detection and treatment of disease. Early detection may lead to the elimination of the disease or the retardation of the disease's progress, thereby preventing further complications, more disability and communicability of contagious diseases. One of the major practices of secondary prevention is the mass screening of asymptomatic persons. These persons may be high risk or from the general population.

Tertiary Prevention is the reduction of disability by attempting to restore effective functioning. The major approach is rehabilitation of the disabled individual who has realized some residual damage as the result of a disease or accident. The goal is to work toward "maximal utilization of the afflicted person's residual capacities, with emphasis on his remaining abilities rather than on his losses."

The three levels of prevention apply to all populations, regardless of age or specific characteristics, such as ethnicity, race, sex, socio-economic level, occupation, etc. For example, immunization against diphtheria is generally administered in infancy and early childhood. Influenza vaccines are strongly recommended for the elderly during periods of high risk. Accident prevention is an essential during early childhood as it is during adolescence and young adulthood. And so on.

Other characteristics of the population (e.g. ethnicity, race, sex, etc.) are taken into account in the application of prevention strategies and practices. For example, the prevention of genetic disorders (e.g. Sickle cell anemia or Tay-Sachs disease) must consider the high risk factors of race or ethnicity. At one time cancer of the lungs associated with smoking was primarily a disease of males. A recent report from the National Institutes of Health indicated that if the proportion of women who smoke does not decrease and current trends continue, experts predict that lung cancer will surpass breast cancer as the leading cause of cancer mortality among women by 1983.

Preventive Medicine and Epidemiology

Preventive medicine (also known as population medicine) is concerned with the health of a defined community. It requires specific techniques and skills in addition to those needed for clinical practices. Clinical and population approaches to health and disease are highly interrelated and, together with the basic sciences, complement each other (Mausner and Bahn, 1974). The chief focus of preventive medicine is the community. But it depends upon a systematic way of studying both the diseases present in the community and the patterns of the delivery of medical care. Epidemiology is the specialty which provides the systematic approach to study of disease and health care delivery in the community.

Though the past focus by epidemiology has been on the study of infectious diseases in the population, its principles

and practices are being applied to other areas of human disorders. By examining and analyzing the extent and types of illness and injuries in communities and the factors which influence their distribution, epidemiology holds out the promise that the causes of disease can be determined. When the cause is known, then preventive measures can be effectively applied.

Incidence and Prevalence of Human Disabilities

Incidence is a measure of predictability. It is a determination of the rate at which people without disease or disability will develop the affliction during a specified period of time. Prevalence is a measure of the number of people in the population who **have** the disease or disability at a given point in time. Therefore, incidence is the rate at which new illness or disability occurs during a specified period of time. Prevalence informs us about the amount of illness or disability existing at a given point in time in the community.

There are several cautions which one should take in utilizing the current estimates about incidence and prevalence of human disabilities.

1. Human disabilities are categorized arbitrarily by different authors. The categorization used here may differ from that used by other prevention specialists.

2. Estimates are often based on a diversity of studies and sources of information. Some incidence and prevalence estimates appear to be quite sound because they are based on replicated studies. Others are based on one study or on a small population and therefore must be used with extreme caution.

3. The matter of definition of human disabilities is a serious problem. Definitions differ from researcher to researcher, from area to area, and from country to country. Though there has been considerable effort given to the establishment of consistent and valid definitions, the problem still remains, especially in such areas as mental illness and social problems.

4. The use of broad and general population estimates should be for the purpose of obtaining a sense of the magnitude and the parameters of the problem in the population.

With these cautions in mind, the following information is offered according to five types of human disabilities; mental retardation, mental illness, physical disabilities, communicative disorders and social problems.

Mental Retardation

There are many definitions of mental retardation but the one that is commonly used is as follows: Mental retardation manifests itself as a disability in reasoning skills arising from a disorder in brain development or functioning and resulting in a lessening ability to learn, to care for oneself, and to make sound decisions about the everyday problems of life (Fotheringham and Morrison, 1976). For purposes of quantifying the condition, researchers have used these criteria for identifying the mentally retarded person: individuals who repeatedly score 84 or less on standardized IQ tests or who have a significantly reduced level of social maturity. Among those so classified, about 80 percent are termed "educable," that is persons capable of learning new skills but at a somewhat slower rate than average learners. The remaining 20 percent include a large number of persons termed "trainable"--persons who can be trained in the basic skills that will enable them to handle routine tasks, such as eating, dressing, and certain kinds of vocational activities. Only a small group of the retarded are unable to benefit from training activities because of the severity of their problems.

The incidence of mental retardation in the population is estimated to be 3 percent or 30 persons with mental retardation out of a population of 1,000 (Birch et al, 1970). In 1977, the prevalence of mental retardation in the United States was estimated at 6 million Americans (NIH Report, 1977). Also, between 1 and 2 million were estimated to be profoundly handicapped.

Mental Illness

In order to understand the nature of mental illness, one must look at the continuum of mental health to mental illness. Many people have attempted to define mental health but most agree that it refers to satisfaction with one's position in life, receiving a reasonable amount of gratification from what one does socially and occupationally. Therefore, mental health is a relative matter rather than something that can be measured in absolute terms. This is in part because mental health is the sum of many contributing factors. The mental health status of a particular person is determined by his genetic make-up and by all the experiences he has had since birth. One can think of the range of mental adjustment as a continuum:

mental health.....mental illness

At the left is the well-adjusted person; at the right, the person who is unable to function adequately because of serious emotional problems. The rest of the continuum represents persons with a variety of symptoms and differing degrees of functional ability. For example, an individual may have psychotic symptoms but has learned to control them sufficiently so that he can maintain a job and support himself. Another individual may have only neurotic symptoms but is unable to control them. He is so distraught that he spends almost all of his time seeking help and cannot concentrate on productive activity.

The President's Commission on Mental Health has reported that at any give time, up to 25 percent of the population is estimated to be suffering from mild to moderate depression, anxiety, or other emotional disorders. In 1975, 3 percent of the population or almost seven million people sought treatment by specialists in mental health and one to

two million were hospitalized for mental problems that year. Depression and manic depressive disorders are among the most severe types of mental illness in terms of prevalence, economic cost and mortality. Of the 29,000 suicides recorded in the U.S. each year, more than 80 percent are determined to be caused by depressive mental illness. Severe depressions or manic excitability disables two to four of every 100 adults at any given time.

Physical Disabilities

Physical disabilities refer to some abnormality in one of the organ systems that seriously reduces an individual's physical functioning or terminates physical fucntioning to the point of rendering the individual functionless. The six most common conditions which result in physical disabilities are spinal cord injuries, head injuries, stroke, fractures (particularly hip fractures), amputations (particularly above-knee amputations), blindness and rheumatoid arthritis. The Public Health Service defines disability as follows: "Disability is any temporary or long-term reduction of a person's activity as a result of an acute or chronic condition. It is often measured in terms of the number of days that a person's activity has been reduced (Public Health Service, 1979)."

In 1977, 12.5 percent of the population or 27,500,000 Americans reported limitation of activity resulting from a chronic condition or physical impairment. Of the number reporting, three percent of the young people were limited in activity while 43 percent of the elderly reported activity limitation. Actually, 17 percent of the total population of the elderly in the United States were unable to carry on their daily activities because of chronic condition or impairment. These data from the Health Interview Survey must be interpreted with care.

Communicative Disorders

Though hearing disorders are usually grouped under Physical Disabilities, they will be considered under the area of Communicative Disorders because of their direct affect on human communication.

Five types of disorders are identified: disorders of phonation, fluency, articulation, language and hearing. Estimates of incidence and prevalence are as follows:

1. Disorders of phonation: Refers to voice quality and voice production difficulties. It is estimated that one to one and one half percent of the total school population possess voice problems serious enough to require professional attention (voice therapy). (Wilson, 1979).

2. Disorders of articulation: The number of children and adults with chronic and persistent articulation difficulties is quite small. It is estimated that about two per cent of the school age population above the age of eight possess articulation disorders severe enough to require professional services. Since most articulation difficulties do not persist after the age of eight, the percentage of adults with articulation problems is probably between one and two percent though there is no substantiation of this observation.

3. Disorder of fluency: Fewer than one percent of the U.S. population is estimated to possess chronic problems with the rate and rhythm during the act of speaking. Though stuttering problems represent a small number of speech handicaps, the condition is most disabling and is noted for its deleterious impact on the social and occupational life of the individual.

4. Disorders of language: About two percent of the school age population possess difficulties with the understanding and expression of oral and written language. Children and adults with language problems resulting from bilingualism, Black dialect and other language forms are not included in this category.

5. Disorders of hearing: It is estimated that five percent of the school age population possess hearing disorders with hearing levels in one ear at least outside the range of normal and that from one to two of every 10 in this group will require special education (Eagles et al, 1963). The remaining children will improve through spontaneous recovery or through medical intervention.

The commonly used incidence statistic for communicative disorders is five per cent of the preschool and school age population. It is estimated that in 1977, 2.8 million children between the ages of 2.5 to 17 possessed some form of communicative disorder which was so serious that the problem required some measure of professional attention, if not a program of therapy.

Social Problems

Social problems refer to those conditions which have deleterious effects not only on the afflicted individual but also on other individuals in the community. The most serious disabilities under this category include (1) alcohol and drug misuse, (2) adolescent pregnancy, (3) sexually transmitted diseases, and (4) crime, particularly homicide.

1. Alcohol and drug misuse: Such misuse are behaviors with serious implication for many areas of living. For example, alcohol and drug misuse increase the risk of accidents, suicides, and homicides. They also contribute to family disruption, poor school and job performance and may lead to long-term chronic problems.

About seven percent of the U.S. population over 18, or 10 million adults, are estimated to be problem drinkers. Younger problem drinkers from 14 to 17 years of age represent a similar serious challenge to health care. It is estimated that three million of them are problem drinkers and become intoxicated at least once a month.

Drug abuse was virtually unknown among young people in 1950. Before 1962 only two percent of the U.S. population had any lifetime experience with illicit drugs. Then the American society began to experience a drug epidemic. By 1977, 60 percent of 18-25 year olds had tried marijuana, 20 percent had tried stronger drugs, such as cocaine and hallucinogens. Though actual prevalence is difficult to obtain, it is estimated that in 1978, there were 450,000 heroin

addicts and 30,000 sedative-hypnotic addicts (Surgeon General's Report, 1979).

Of particular concern are the statistics regarding marijuana use by teenagers and young adults. Ten percent of high school seniors reported daily use of marijuana. When this drug is used in combination with alcohol, the risk of accidents considerably increases.

2. Adolescent pregnancy: Adolescent mothers are at high risk. They experience a greater risk of bearing low birth weight infants, face significant social problems, disrupt their schooling, and realize high rates of repeat pregnancies and public dependency. The major underlying problem is inadequate knowledge of and access to information on sexual behavior and family planning.

It is estimated that 25 percent of American teenage girls have had at least one pregnancy by the age 19. Each year about one million adolescents under the age of 19 become pregnant. Though birth rates for teenagers aged 16-19 are declining, they are increasing for girls under 16.

3. Sexually transmissable diseases: Although there has been some recent improvement in the overall incidence of gonorrhea and syphilis, both diseases still pose a serious health problem. Both diseases are increasing among adolescents. It is estimated that 8-12 million cases of sexually transmitted diseases occur each year. Of that number, 75 percent are found in the age group from 15-24. These diseases result in an estimated 75,000 women each year of childbearing age who become sterile (Surgeon General's Report, 1979).

4. Crime: Crime in the United States has reached epidemic proportions. It takes its toll on the American public by the continual threat of violence and bodily harm, by increasing the price of insurance and police protection (and thereby goods and services) and by reducing the general quality of American life. U.S. Department of Justice reported that a violent crime occurred in our country every 32 seconds (U.S. Department of Justice, 1976). More than 11,300,000 major crimes were committed in 1976.

Based on reports by the Federal Bureau of Investigation, on the average, one in every 20 persons may be involved in a major crime. These include murder, rape, robbery. Of particular concern is homicide. Murder accounts for over 10 percent of all deaths among adolescents and young adults. In 1977, 21,000 Americans were murdered; 25 percent of the victims were in the age range of 15-24, placing this group at greater risk than the rest of the population.

The U.S. homicide rate is among the highest for industrialized countries: U.S.--10.2/100,000; France--.9/100,000; Great Britain--1.0/100,000; Sweden--1.1/100,000; Japan--1.3/100,000.

One of the major reasons appears to be easy access to firearms by Americans. From 1960-74, handgun sales increased four times, from 1.5 million to 6 million per year. During the same period, the homicide rate increased from 4.7 per 100,000 to 10.2 per 100,000 for the overall U.S. population.

Causes of Human Disabilities

Each of the major categories of human disabilities may be caused by one or more of many factors. The primary factors which have been the subject of careful study and which can be altered to reduce affliction are genetic disorders (disorders due to heredity); perinatal complications (disorders resulting from problems encountered during pregnancy and the birth process); acute and chronic illness (disorders resulting from fatigue, infections, cardiovascular system disease and stroke, gastro-intestinal disease, neoplasms, and so on); accidents (disorders resulting from injuries sustained at home, at play, at work and while driving); violence (disorders caused by crime and war); environmental quality problems (refers to afflictions caused by air and water pollution, noise pollution, and general toxic contamination of the environmental at home and at work); drugs, tobacco and alcohol (resulting in disorders of addiction, reduced health status, and often death; and nutritional disorders (resulting in obesity, cardiovascular disease, and cancer). Other factors of interest to researchers include deleterious child-rearing practices, familial-cultural beliefs which are due to ignorance and superstition and expose the individual to high risk, unsanitary living conditions, inaccessibility of adequate medical care, and stress due to personal and social dissatisfaction.

The prevention specialist must be thoroughly acquainted with the causes of human disabilities and with our current knowledge and ability to inhibit or reduce the effects of these causes.

Prevention Strategies

To mount a comprehensive community program of prevention, one should be aware of the type and range of procedures and practices available. If we focus on only primary and secondary prevention measures, ten strategies are identified.

1. Immunization

This is the most effective tool in the prevention of infectious diseases. Active artificial immunization is the procedure by which we duplicate the favorable aspects of response to infection without the full consequences of the specific disease. Though there are immunizing agents (vaccines) for 25 disorders, the American Academy of Pediatrics recommends only seven vaccines for routine use in the United States. Table II lists the recommended schedule for immunization of normal infants and children (American Academy of Pediatrics, 1977). In making the recommendation of the vaccines for routine use, several factors were considered: (1) the present-day risk of the disease; (2) the benefit to the individual and society in preventing the disease; (3) the efficacy, safety, cost and availability of the vaccine; (4) the alternatives to vaccine in prevention of the disease; and (5) the special needs and characteristics of the group or individuals to be immunized. The Committee on Infectious Diseases of the Academy of Pediatrics made its recommen-

dations for infants and children who receive their health care in physicians' offices, clinics and similar facilities where there is an expectation of regular attendance

The cost effectiveness of this strategy has been documented extensively in the scientific literature. A dramatic illustration is provided by our experience with rubella.

In 1963-65, the U.S. experienced a rubella epidemic which left 20,000 to 30,000 children with serious handicapping disorders. The estimated special educational cost is about $1 billion for the care of the afflicted children (Calvert, 1969). The epidemic resulted in 5,500 visually handicapped, 12,000 hearing impaired, 1,250 deaf-blind, and 1,250 retarded/crippled children. In 1969, the average cost for special educational care for a deaf-blind children was $13,500 per year. For these children alone, the financial outlay would be about $15 million per year. If some agency like the U.S. Public Health Service had conducted a mass immunization program, the epidemic would have been prevented or at least reduced sufficiently so that few children would have been afflicted. One recommenation was to immunize all prepubescent females at a rate of two million per year in order to reach the entire at-risk population on an annual cohort basis. At the cost of less than $ .50 per dose, the total vaccine cost would be about $1 million per year. Over a ten year period, the cost would range between $15 to 20 million (accounting for inflation between 1960-70). Even if the costs were twice that amount, there is no comparison between the cost of the preventive measure and the real costs of providing total care for severely handicapped children. And, we have not mentioned the degradation of the quality of life resulting from the 1963-65 epidemic, an incalculable price for any human to pay.

There are a number of developing countries still procrastinating about routine immunization against infectious diseases and continue to annually add many severely handicapped and disabled children and adults to their already overburdened population.

2. Genetic Counseling

Hereditary factors play an important role in the development of a number of disabilities. It is estimated that 521 diseases result from an autosomal recessive mode of inheritance (McKusick, 1978). These include the more commonly known diseases of phenylketonuria (PKU), Tay-Sachs disease, and hypothyroidism. About 50 defined syndromes have been found to be related to hereditary hearing loss (Rand Report, 1974).

In order to reduce the incidence of disabilities associated with genetic factors, genetic counseling is the recommended preventive measure. Genetic counseling has been defined as follows:

Genetic counseling is a communication process which deals with the human problems associated with the occurence, or the risk of occurance, of a genetic disorder in the family. This process involves an attempt by one or more appropriately trained persons to help the individual or family 1) comprehend the medical facts, including the diagnosis, the probable course of the disorder, and the available management; 2) appreciate the way heredity contributes to the disorder and the risk of recurrence in specified relatives; 3) understand the options for dealing with the risk of recurrence; 4) choose the course of action which seems appropriate to them in view of their risk and their family goals and act in accordance with that decision; and 5) make the best possible adjustment to the disorder in an affected member and/or to the risk of recurrence of that disorder (Fraser, 1974).

Though this preventive measure is increassing in significance and impact, it presents many difficulties which must be surmounted before its real potential is realized. The national genetic screening program to detect sickle cell anemia, estimated to be the largest-scale genetic screening and counseling program in existence, has demonstrated that there are many unanticipated and frequently negative consequences. These include (a) that mass screening raises issues related to public education, community relations and the private lives of the identified trait-carriers which are in need of resolution; (b) the identified person's reactions are often unfavorable; (c) there may be community resistance; (d) there is the problem of stigmatizing the person who carries the trait; and (e) the eugenic questions of such a program are very serious and remain unresolved today (Culliton, 1972).

3.Prenatal Care

The important services needed during pregnancy include a thorough assessment of any special risks because of family history or past personal medical problems; physical examination and basic laboratory tests; aminiocentesis where indicated; and medical counseling on nutrition, smoking, alcohol use, exercise, sexual activity, and family planning (Surgeon General's Report, 1979). In 1977, 74 percent of the population of pregnant women received prenatal care during the first three months of pregnancy. Of the remaining women, too many received care only during the last three months of pregnancy. One to two percent received no prenatal care and were at greatest risk.

Many of the problems women experience during pregnancy can be avoided, corrected, or considerably reduced if quality prenatal care is received. For example, eight percent of women at high risk of having a low birth weight infant can be identified by the physician during the first prenatal visit. Immediate steps can then be taken to reduce the risk of developmental problems or perhaps death.

4. Mass Screening and Early Identification

The process of early identification and appropriate follow-up assessment and treatment is an essential preventive strategy. Since its purpose is to select individuals in the early stages of a disease or disorder, this strategy is technically referred to as Secondary Prevention.

Early and accurate identification of potentially handicapping conditions is one of the most important prevention

strategies but unfortunately underused and underrated. Vision and hearing screening of school children is considered one of the best of the formal identification programs. But it is far from universal for school-age children and often poorly implemented (Rand Report, 1974). The early identification of sensory disorders should be a priority if we wish to provide effective and successful treatment and special educational programs for the visually and hearing handicapped. For example, preschool hearing impaired children should receive early language training and development in order to function effectively in the regular classroom when they become of school age.

Mass screening for a range of disorders should be instituted on a systematic and periodic basis, focused primarily on young children and high risk populations of adolescents, young adults and adults. Provision for follow-up diagnosis and treatment of those who fail the test must be made. Also, it is recommended that high risk registries be established, especially for children at risk in the 0 to 5 year age group. After high-risk infants are screened at birth, they should be screened one to three times between birth and age 5, and once again upon entering school.

5. Family Planning

It is reported that of the more than four million pregnancies a year in this country, one million are terminated by legal abortion. Of the more than three million births, it has been determined that one-third are unplanned. These statistics imply that half of all pregnancies are unplanned and many are unwanted (Surgeon General's Report, 1979).

Unplanned pregnancies often lead to deleterious effects on the child, the mother and the family. It may affect the health of the child and the social well-being of the mother. It has been observed that births which are planned are more likely to realize a higher health status and the infants become the recipients of quality parental love and support needed for healthy physical and emotional development.

Family planning agencies usually recommend that families have no more than two children and only at maternal ages between 20 and 34. To control unwanted pregnancies, supportive counseling and sex education are provided.

6. Proper Medical Care

Whether an individual is in touch with a private physician or a health care agency, accessibility to a health care resource is essential in maintaining good health. Though there is some current controversy about the efficacy of annual physical examinations, it is recommended that each member of the population receive annual check-ups as a screening routine. Those found with disorders should receive prompt and responsible follow-up medical care. Another value of the annual check-up is that it provides the health care specialist with the opportunity to advise and educate the patient about ways to prevent disorders and maintain good health status.

As a prevention strategy, it is good practice to encourage each individual to maintain a periodic contact (we recommend at least once each year) with a health care provider who is aware of the patient's history and thereby can keep track of pertinent developments in the health care of the individual.

7. Public Education

This refers to education of the community for knowledge about prevention. The objectives of public education are to develop a prevention-oriented person who (1) has broad knowledge of prevention strategies, (2) is strongly motivated to move from the state of knowledge to action, behaving in ways which lead to and maintain good health, and (3) understands the political process and what is necessary to effectively influence key individuals and social institutions to practice prevention.

Information about prevention should be disseminated as widely as possible at the local, state and national levels. The use of mass media (television, radio and the press) will play an important role if the campaign is systematic and continuous, if the exposure of the information to the public is appealing and receives priority status (that is, prime time on radio and television and front page coverage in newspapers), and if key individuals are associated with the campaign. In addition it has been found that face-to-face instructional programs enhance the power of the media program which is attempting to promote positive health behavior in the population (Maccoby, 1980). The intensive face-to-face instructional program for certain segments of the community would reinforce the concepts communicated by the media campaign. In a study by the Stanford University Heart Disease Prevention Program to reduce risk in heart disease through the use of media and face-to-face instructional programs as a supplement to the media campaign, the content of the instruction program was composed of information units on heart disease and through the use of persuasion in the context of social learning and self-control training procedures, individuals were encouraged to change their lifestyles and health behavior (Maccoby, 1980'.

8. Education in Preparation for Life

This strategy refers to the introduction of information about prevention at all levels in the school system with the purpose of preparing young people for a more healthy life, both physically and mentally. Through appropriate instructional units, teaching aids and observations, elementary and secondary school students should obtain sufficient knowledge about health and the prevention of illness, injury and disability.

Also, curriculum units should include education for parenthood, preparation for the major transitions in life (adolescence, adulthood, older adulthood, leaving home, getting married, and so on) and preparation for the major crises in life (death of a loved one, birth of a child, financial difficulties, loss of a job, sexual problems, and so on). Such information should be introduced in a manner and sequence which is appropriate for the age and maturity of the students. Christoplos and Valletutti view education as the "essential means of prevention" and call for a massive

education program to teach individuals to behave in ways that miniumize the likelihood of their becoming disabled (1979, p. 9).

9. Environmental Quality Control

There is tremendous public interest in conserving our natural and national resources and the quality of our environment. As a developed country, the U.S. has witnessed the accumulation of vast amounts of waste and unwanted waste products which may contaminate our air and water and which may become detrimental to human health. Pollutants also limit desirable living space, interfere with sanitation and adversely affect the full enjoyment of the natural environment. Since these problems do not respect geography or political subdivisions, it is logical that the federal government intervenes to assist states in achieving and maintaining a uniform program of environmental quality control. It appears, however, that the federal government has been more ambitious to impose tighter standards than the states. Therefore, there is need for continued vigilance about the enforcement of current laws and the need for new and more effective measures to protect the environment for healthy human use.

In planning for the improvement and maintenance of environmental quality, the following priorities are recognized: (1) the protection of the community water supply for consumption, recreation and other appropriate purposes; (2) the control of air pollution; (3) disposal of refuse and waste; (4) occupational health and safety; (5) noise pollution; (6) food and milk control; (7) radiation protection; (8) control of toxic substances in buildings (such as lead paint, asbestos in ceilings of schools, etc.); and (9) low cost housing (Kruse, 1976).

10. Social and Educational Programs to Improve the Quality of Life

This strategy suggests the need for special programs for individuals at certain transition stages in life, focussing primarily on the potential problems of adults. The purpose of the strategy is to provide assistance through education and counseling to individuals facing the prospect of stressful and disappointing experiences. These experiences may include early signs of stress and difficulty in marriage, indications of difficulty with job performance, the prospect of retirement, concern about one's narrowness in perpective and interests and the need to broaden personal interest in the arts, music, drama, dance, and literature, and dissatisfaction with the unattainment of personal and social goals.

In recent years there has been a growing concern on the part of business and industry for their retirees. After leaving their places of employment for retirement, loyal and dedicated employees quickly becomes debilitated, depressed and unable to cope with their "retired status." As a result, the field of retirement counseling has developed rapidly, providing programs of retirement planning not only for those who are about to retire but also for the younger workforce population.

The growing community interest in the elderly has resulted in laudable attempts to improve the quality of life of this increasing population of citizens. Efforts are underway to bring our elderly into the mainstream of community life rather than isolate them in gerontological ghettos. Educational and social programs have been developed to meet expressed personal needs of senior citizens for a better quality of life.

Such programs could be provided by community schools, religious institutions, the courts, legislative bodies, business and industry, and other community institutions.

Planning and Implementing a Prevention Program: General Considerations

With the preceding background and information, let us consider the planning for and the implementation of a community-wide prevention program. Given the nature of our decentralized governmental systems and the disarray of our current health care system, a community plan is the best approach and must evlove from the "grass roots" if it is to be effective. That is, we cannot expect a governmental agency at any level to assume the full responsibility to institute a comprehensive community program of prevention. Success will depend upon the interest, initiative and cooperation of a diverse group of persons in each community. Furthermore, it must be understood that prevention cannot be a "once in awhile effort" -- it should be instituted as a comprehensive, coordinated and continuous program, systematically installed and administered.

Any effort of the magnitude and intensity suggested here will require that a number of conditions are met. These include:

a. Recognize that a community is comprised of publics; not one "general public" but many small publics, each representing a specific neighborhood, religious group, lodge, professional organization, business, or civic group. The planners and developers of a community based prevention program must deal with these small publics.

b. There should be a careful study of the community's power structure, identifying those members whose approval is often essential for the success of any community project.

c. Use the information dissemination process from mass media to face-to-face meetings with each of the small publics to explain the purposes and ramifications of the prevention program.

On a community level, leaders will reject a proposed program if they cannot understand how the program will meet community needs. They may be sympathetic to the general aims of the proposal but may judge that their community is not ready for such an undertaking. Therefore, a careful and deliberate campaign of persuasion must be initiated to enlist the endorsement and support of key individuals in the community. Failure to recognize this principle explains, to large extent, the notable difficulties faced by health officials in promoting fluoridation in the 1950s (Green, 1961).

Specific Procedures for Instituting a Comprehensive Prevention Program

The suggested procedures which follow were developed for the specific needs and characteristics of the United States. Other approaches may be more relevant and feasible for countries with different governmental structures and citizen attitudes and expectations. As mentioned earlier, because of the current disarray of resources in our health care system and because a centralized governmental approach to prevention is untenable, we recommend a community-based approach. Community is defined as a population of individuals living in a particular goegraphical area and having a history of social, economic and political interests in common. The community could be a village, a neighborhood in an urban area, a city or a county. Any geographical area larger than a county will defeat the purpose of developing a prevention effort which evolves and receives the support of individuals at the "grass roots."

1. Prevention Program Leadership

Though one may conclude that a physician or another health care provider should take the initiative to institute a community prevention program, this may not be the case. Any knowledgeable and determined community citizen can organize a leadership committee to plan and institute the program. The leadership committee (or the Prevention Program Committee) should represent the diversity of composite interest groups in the community. Thus, the committee should be composed of representatives from key religious, professional, educational, business, political, governmental and health provider groups. It is essential that the professions of medicine, dentistry, nursing, social work, rehabilitation, psychology, speech pathology and audiology, etc., are well represented on the committee to provide support for the health care groups and to offer professional advice in the development of the program.

2. Prevention Program Development and Implementation

Once the community prevention program leadership has been identified and organized into an operating committee, a number of steps should be taken in order to move in a systematic and orderly fashion from intentions to implementation. These steps are as follows:

a. Analysis of Community Prevention Needs.

The first step is to identify the gap between current efforts in prevention and the realistic needs of the community. Conduct a community-wide study of the current status of prevention efforts. Consult with governmental public health officials, the regional health systems planning agency, the local chapters of professional organizations representing the health care fields (medicine, nursing, dentistry, nutrition, etc.) and public and private schools and colleges. Develop a detailed and accurate report of what is currently being done to prevent human disabilities in the community.

The next step is to obtain an inventory of all pertinent resources in the community which could contribute to the prevention program. Include individuals, agencies and groups which provide the potential for implementing essential prevention strategies. For example, the local society for the hearing impaired may serve in a mass screening effort for early detection of hearing loss in the population.

Following the analyses of the current prevention efforts and the community resources, the planning group should prepare a comprehensive report of the magnitude of the prevention needs in the community. The committee should hypothesize about future needs, projecting for at least five years.

b. The Long Range Plan

It is at this point that the Prevention Program Committee must decide whether to mount a comprehensive program or begin with a more modest effort, the selection of one area of need, such as the prevention of mental illness or mental retardation. Some communities may understandably feel overwhelmed by attempting to address all needs. Once this decision is made, then the Plan should be promptly developed.

Based on the analysis of needs, the planning committee should state prevention objectives in measurable terms. For example,

"Objective #1. Reduce the incidence of hearing loss in preschool and school-age children (0-17) by 40 percent in five years."

"Objective #2. Reduce the incidence of injuries by home accidents by 50 percent in five years."

Then, prevention strategies associated with stated objectives should be delineated. For example,

"Strategy #1. Plan and implement a systematic televison, radio and newspaper campaign to inform the community about the prevention program and its role in implementing a successful effort (Public education strategy)."

"Strategy #2. Introduce prevention units throughout the elementary and secondary school curriculums to raise student awareness about their protection against future disability (Education in preparation for life strategy)."

The objectives and strategies should then be placed in a timetable which delineates when activities should be instituted and the milestones toward the successful accomplishments of objectives. In the Plan, realistically detail the problems the community may face in implementing the program. Address the questions of community cooperation and the availability of resources, including financial resources.

Include a description of an evaluation plan to systematically assess how well the Plan is being implemented. The evaluation component is essential for three reasons: (1) it allows the committee to determine the feasibility of the Plan, (2) it allows for periodic correction of the direction of the Plan if it is found that the Plan is not moving successfully toward the attainment of the objectives (and thereby avoid costly mistakes), and (3) it develops community

respect and confidence for the Plan if it is systematically assessed and the results are reported. This sould be part of the public relations aspect of the prevention effort.

3. Community Review and Approval of the Plan

After the Plan has been developed, it should be rewritten into a readable and clearly delineated **draft** plan of action for public distribution, review and approval by the total community. The use of public media at this stage is essential. The purpose is to alert the community citizens about the prevention effort and their participation in the development of the Plan. The community-based approach recommended here will require public participation on a periodic basis. After a number of public hearings, the final draft of the Plan should be written. It will be this edition which will direct the prevention effort with the proviso that changes are inevitable as the Plan is implemented and evaluated. The publics will be consulted through the media and through the recommended periodic hearings to discuss the progress of the prevention effort.

4. Implementing the Prevention Program

Once the Plan has been carefully developed, reviewed, and receives approval by the community, it is advisable that the Prevention Program Committee be incorporated into a committed organization (the Prevention Program Organization or the PPO) with a responsible and dedicated staff. The Prevention Program Committee should then appoint a full-time director who is a health care professional knowledgeable about prevention and the implementation of health-related programs in a community. The director should have a competent staff capable of successfully administering, evaluating and reporting the Plan. Staff needs should be decided by each community on the basis of the Plan and the available resources. But one must caution against the tendency to place too little emphasis on the importance of adequate staffing to administer the Plan and handle the complex and demanding issues related to good public relations.

Assuming initial favorable response by the community, the Prevention Program Organization will be responsible for maintaining this interest and support throughout the implementation stage. Of course, such an effort will be difficult as the plan progresses because public interest has a tendency to wane and move from crisis to crisis, from one major issue to the next. Also, as the history of problems develops with the Plan's implementation, various segments of the community may become disenchanted or disillusioned with the effort and become critical. The Prevention Program Organization must prepare for these possibilities and work continuously to maintain the heightened interest and support of the community.

The organization must collect all pertinent data during the implementation stage so that accurate reports of activities, successes and failures, are developed. Also the evaluation of the Plan must be continuously conducted and intelligently utilized to "correct" the Plan as necessary and to inform the publics about the progress of the program.

At the end of the implementation stage as delineated by the Plan, a final report should be written for public consumption. The report should contain an assessment of the success of the Plan and recommendations for next steps in the prevention of human disabilities in the community.

Summary

The broadly expanded field of prevention is defined according to three levels of activity. Primary prevention is the inhibition or elimination of disease, injury and diability before it affects the individual. Secondary prevention refers to early detection and prompt treatment of disease and disability. And, tertiary prevention is the reduction of disability by attempting to restore effective functioning.

Five major categories of disability and the reported incidence and prevalence of each disability are identified: mental retardation, mental illness, physical disability, communicative disorders, and social problems. The broad array of possible causes of disability is reviewed to include illnesses, injuries and environmental problems.

The potential contributions of the ten major primary and secondary prevention strategies to the elimination or reduction of disability in the population, are discussed. These strategies include immunization, genetic counseling, prenatal care, mass screening and early identification, family planning, proper medical care, public education, education in preparation for life, environmental quality control, and social and educational programs to improve the quality of life.

Finally, recommendations for instituting a prevention program at the community level are presented. It is the thesis of this paper that a community-based program is the most appropriate approach for the United States. Given the current disarray of our health systems and the decentralized nature of our governmental processes, a prevention effort is best initiated and maintained at the community level.

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Excerpts of Reviews and Comments

The following are excerpts of reviews, comments and questions raised by the Switzer Fellows. These are presented to further stimulate thinking as well as action as it relates to the content of the chapter by Dr. Michael Marge.

"An examination of the causes of impairment, particularly those associated with disease, suggest that on an international plane we can hope for results only when we attack the problems on a regional -- that is to say international --scale. Polio, for example, can be eradicated -- but only when the nations in a region that can be controlled are willing to engage in a program that is coordinated in time and saturation. Until now, political and other considerations have been given greater weight than the requirements of an immunization campaign. The world must make its choices. This merits discussion.

The paper, comprehensive as it is, does not address the special problems of countries in the early stages of economic and social development. It is in those countries that most impairment comes about, that impairment most often leads to disability, and that handicaps are least understood. If our project is to illuminate these issues on an international basis, it will be essential to examine experiences in other areas -- and to ask whether the United States cannot perhaps learn from the process about how better to attack its own problems as well as how better to assist others."
--Norman Acton

"The basic thesis of this paper, that of community-based preventative health care programs, is not only most timely and appropriate as the best approach in the United States, but throughout Latin America as well. The needs are the same, although perhaps, at varying levels of development throughout the Americas. It is, indeed, imperative to plan and implement **comprehensive,** coordinated and continuous systematically installed and administered programs using **significant** members of each individual community to bring such programs to fruition. A key factor is the identification of such community members whose approach is essential for success of **any** community project.

In Latin America, as in the United States, preventative care is the most inadequate aspect of the health care system, but more so, infectious diseases are still prevalent, due in great part to a lack of comprehensive immunization program. Perinatal care in the first trimester of pregnancy is less than 50 percent in Latin America as compared to 74 percent in the United States.

The ten major primary and secondary prevention strategies to eliminate or reduce disability in the population discussed encompass most valuable means of dealing with such monumental problems. These strategies offer strong, viable alternatives and approaches for using the community as the chief focus for prevention. Such strategies also based their strength on the individual and small groups to achieve stronger and healthier individual and family lives."
--Rodrigo Crespo-Toral, M.D.

"Developing countries struggling for economic growth are attempting to accelerate industrialization, often without the range of safety controls built in by governmental oversight in the already industrialized world. The International Labour Organization has just added 16 more items to its list of occupational diseases. The most important of these, hearing impairment caused by noise, skin and parasitic diseases in the health field, illustrate the need to strengthen disability prevention on the job. Similarly, a focus on disability prevention at work can reduce accidents as a cause of severe impairment. This might usefully be shown as a distinct prevention strategy area."
--Susan Hammerman

"The international implications of this extraordinary paper are great. The number of foreign organizations working at one time in any given developing country may range between 20 and 500. The projects are mostly directed toward 'aid' - a very few deal with prevention.

Since populations of developing countries will have multiplied 2 to 5 times by the year 2000, foreign aid can never 'catch up' to the basic survival needs of general populations, let alone the disabled. Through assistance in the areas of prevention, developed nations and international organizations can offer significant aid to the health and the economic growth of developing countries.

Dr. Marge's descriptions of the faltering steps taken toward prevention of human disabilities in the United States give a hint of the difficulties to be expected when trying to offer projects of this nature to the third world."
--Jeanne R. Kenmore, Ph.D.

"It may be that the development of the fields of epidemiology and preventive medicine in the 19th centruy ushered in the major or organized period of prevention, but human history will record that many primative or non-literate people practiced a form of preventive medicine."
--James S. Peters, II, Ph.D.

"This is a particularly good synthesis paper on the subject. The suggested action proposals are valuable for planning strategies for the 80s. His proposed ('small is beautiful') Schumacher-style approach coincides with the present sentiment for decentralization of decision making and action. Notions about community self-help, local agency coalitions and networking are gaining currency, as ways of dealing with the complexity within the human service industry.

The discussions in the Seminar should include consideration of the central role and support efforts needed to implement the action approach suggested - without which local countries and communities are unlikely to succeed."
--G. Allan Roeher, Ph.D.

"A community-based prevention effort supported by community leaders, is probably the only realistic way to combat the forces which work against prevention education. In the United States, a national effort would be undermined by special interest groups concerned with protecting their own positions. Health prevention efforts are then clearly a 'political' problem in the United States. How then are we to encourage prevention efforts in developing nations?

Can a community-based prevention effort be encouraged in developing nations where community facilities are extremely limited? How can community-based prevention effort overcome the religious, economic and social taboos, both in developed and developing nations? How can community leaders be encouraged to overcome their reservations about prevention to lead their communities into comprehensive prevention efforts? Can teachers, doctors and other professional positions be taught prevention in their education programs?"
--Robert H. Ruffner

Summary of Recommendations

The following is a brief summary of the recommendations and implications for action as developed by the Switzer Fellows as it relates to the topic of the second chapter. (The recorder was Dr. James S. Peters, II)

I. Policy and Program Development

a. With few exceptions, it is recognized that preventive care is the weakest link in the program of comprehensive services for the disabled throughout the world. It is recommended, therefore, that prevention receive the same priority as primary and acute care in the development and provision of health and health-related services by all nations.

b. There is a need for timeliness or staging in the development of prevention programs in various nations. At the same time that primary and acute care is improved and expanded, prevention should be increased.

c. With few exceptions throughout the world, medicine is practiced primarily as a treatment-oriented profession rather than as both treatment-oriented and prevention-oriented. It is recommended, therefore, that medical schools introduce into their pre-service and in-service training programs components about prevention.

d. It is recommended that governments strengthen and promote family life as the basic building block of society and as the organization which will result in better opportunities for healthy social, emotional and physical development.

e. We encourage the development of a more responsible media, as we recognize the important role of the media in promoting good social, emotional and physical health.

f. It is recommended that programs for disability prevention and services use a comprehensive approach to include primary, secondary and tertiary prevention.

g. It is recommended that governments should immediately institute prevention efforts which are comprehensive in the reduction of the incidence and prevalence of all disabilities rather than to focus only on one category of disability at a time.

h. It is recommended that programs for disability prevention and services should include disabled persons on their governing and operational boards or committees.

II. Service Delivery

a. As part of a comprehensive prevention effort, all disabled persons should receive the appropriate rehabilitative service to attain the greatest measure of function within the limits of the impairment. This phase of disability prevention is referred to as tertiary prevention.

b. The UN, World Health Organization (WHO), Organization of American States (OAS), and other international organizations should immediately provide expertise to developing nations in the planning, development and implementation of comprehensive prevention programs.

III. Training (staff and the general public)

a. Public education programs should be instituted using mass media, conferences, and workshops to educate the general public about what each person can do to prevent disability.

b. Governments should introduce information about prevention throughout the public school curricula. Many diseases can be readily prevented with elementary knowledge which should be taught in primary schools

c. As was mentioned above, medical schools should incorporate units on prevention into their training programs.

d. Governments should introduce sex education and units on responsible parenthood into the public school curricula.

e. It is recommended that governments institute a program of training for midwives as a measure to provide the most feasible approach to better prenatal and perinatal care. Such programs should be developed where there is little or no available professional care

f. The family is recognized as one of the most effective units by which prevention programs can be implemented. This potential should be developed.

IV. Research

a. There is an immediate need to test the efficacy of various models of prevention programs in selected sites throughout the world. More data is needed about the problems and the feasibility of certain approaches to reduce the incidence and prevalence of disability in developing countries.

V. Legislation/Government Policy

a. Ten prevention strategies are recognized. Each of the ten should be adopted as government policy and include:

1. Comprehensive immunization programs should be practiced in all nations.
2. Genetic counseling should be available to advise individuals about genetic disorders and available options.
3. Prenatal care by trained personnel (M.D.s, physician assistants, nurses, foot doctors, and other paraprofessionals) should be provided all pregnant women. The avoidance of malnutrition, contagious diseases, drug and alcohol intake, etc., must be urged and monitored.
4. Mass screening and early identification of disease, illness, injury and other impairments should be instituted as a continuous process of secondary prevention in nations throughout the world.
5. Family planning should be instituted which encourages pregnancies between the ages of 20-35, no more than two children per family, and concern for the health and welfare of the mother.
6. Proper medical care for all individuals by developing an infrastructure of health care personnel comprised of nurses, physicians assistants, foot doctors and other paraprofessionals. These personnel should work under the supervision of a physician and rapid referral services should be available for more advanced primary and acute care. All individuals should be seen by a health care worker under a physician's supervision at least one each year.
7. As mentionaed above, the education of the public about prevention and 'life extension' through the media, conferences and workshops should be introduced as soon as possible in any given country.
8. School systems in all nations should incorporate into their curricula units which prepare young people for a more healthy life, both physically and mentally.
9. All nations should take steps to protect their environments by establishing an agency and legislation which are dedicated to the promotion of environmental quality and the eradication of environmental pollutants.
10. It is not enough to save lives. At the same time we must also improve the quality of lives for all individuals from childhood to adulthood. Nations should be encouraged to initiate social and educational programs which help individuals take better care of their health, seek ways to reduce stress in all facets of their daily lives, and enjoy the available opportunities for art, music, dance, drama, literature and other cultural benefits.

b. It is recommended that prevention programs be initiated at the community level because of a better prospect for successful implementation. It is recognized however, that the support of governments is essential to sustain community-level prevention programs. This support should be in terms of policy and funding and, if necessary, enabling or mandating legislation.

c. All governments should prohibit export and import of products which have been judged to be hazardous to animal and human health. (Of particular concern is the export of cigarettes from

the U.S. tobacco companies to Latin American countries and to other parts of the world and of hazardous drugs from one country to another.)

d. All nations should have bans on noise pollution and should institute programs of public education for the protection of hearing.

e. Governments should explore ways in which alcohol consumption is reduced especially among pregnant women. Governments are "partners" in the consumption of alcohol by depending upon alcohol beverage tax as a source of income.

f. Drug education programs should be instituted by the governments throughout the world. This must be an essential part of any prevention program.

g. Governments must enforce strict firearms controls as a means of reducing homicides and disabilities from gunshot wounds.

SWITZER FELLOWS: The leadership at the fifth Seminar included, left to right: Dr. Brockman Schumacher, Chairperson of the Switzer Memorial Committee; Dr. Howard Rusk, host and Fellow; Dr. Leonard Periman, Seminar Coordinator; Dr. James F. Garrett, Chairperson of the Seminar; Dr. Margaret J. Giannini, host and Fellow; and Richard C. Engelhardt, host.

SWITZER FELLOWS: Fellows here are, left to right: Norman Acton, Henry Williams, Dr. Rodrigo Crespo, Gregory Dixon, Barbara Duncan, Dr. Donald Galvin and Dr. James Burress.

Chapter Three
By Susan R. Hammerman

The Assurance of Needed Services and Support Systems For Disabled Persons

Summary Comments

This paper clearly presents the reality of the human tragedy, and the socio-economic impact of disability in the third and fourth worlds. Twelve principles are given which underlie application of the rehabilitation process in any society. Of special interest and value are her practical suggestions for implementing this process in developing countries and her list of needed research.

The general problems are enormous: rapidly growing populations, "young countries" where 50 percent or more of the total population is under 15, lack of transportation through rural areas where 80-90 percent of the people live, centralized governments giving little attention to community services, multiple languages in single countries making education and communication difficult, the inappropriateness of much of our modern technology, the difficulties of conducting surveys to find the handicapped in both urban and rural areas, the problems of jobs for the handicapped in nations with minimal industry and foreign trade and up to 50 percent unemployment, the lack of understanding about child development in general and extremely bad health conditions.

Implications for international assistance are vast. National and international organizations which wish to give assistance should share information on patterns of programs which have worked under certain conditions.

Miss Hammerman's excellent paper suggests ways of translating rehabilitation principles into reality despite the incredible problems that exist.

Comments by Jeanne R. Kenmore, Ph.D.

I. Worlds: The Disability Problem in Context

"Only one world" was a popular phrase just a few years ago to describe the fact that all of us, people of this world, are mutually dependent for survival upon the natural resources of the earth and upon each other. We know, however, that the lives the people of the world live are so very different from one another as to constitute many worlds within our one world. As we try to examine the lives of disabled people in the world today, and the types of services and support systems that are needed to improve the quality of their lives, we must first consider within which world they live.

The Third World. Most people of the world live in developing nations, commonly grouped to form "The Third World". In the decade of the 80's and in the decades beyond, population trends assure that the proportion of people living in the Third World will increase. By the year 2000 almost 5 billion of the world's 6 billion people will live in developing nations; more than one-third of them will be children under the age of 15 years.[1] The facts of life for the one billion children of the Third World today are that seventy percent of the boys of the developing world and only one half of the girls receive a primary education. This compares with eighty-five percent completion of primary and secondary education in the developed world. More than 100 infants of each 1,000 born in the developing world die at birth. In the developed world, infant mortality has been reduced to under 20. The majority of children in the developing world will eat less each day than the minimum they require to grow and develop. Malnutrition accelerates death from exposure to infectious disease such as those long since conquered in more developed areas, including tuberculosis and poliomyelitis. Measles alone kills 400 times more children in the developing world than in the developed. Most significant of all, approximately one-third of all children in the developing world live in rural areas completely beyond the reach of health and social services.

The poet Milton has said, "Childhood shows the man, as morning shows the day." With the limitations of inadequate health care, insufficient food and education, under stimulation and under-utilization applied so early in life, the child's potential for productivity in adult life is significantly reduced. Despite the combined efforts of international development assistance and national development planning, these trends are accelerating. Without a dramatic shift in levels of committment in the future, the situation of people in the Third World will grow increasingly more disadvantaged during the decades to come.

Disabled people have rarely been singled out by society for privileged consideration. More often, and still prevalent in the developing world today, they must live lives inferior to that of others in their communities. They are frequently excluded from social life and opportunity.[2] A recent Rehabilitation International study of UNICEF* on the situation of disabled children, particularly in the developing world, concluded that even when the benefits of development may reach a community, disabled children and their families are the least likely to benefit from any gains in access to improved nutrition, health care, education, social assistance, and employment.

Justice Khrishna Iyer, of the Supreme Court of India, has described disabled people in the developing world as living in a Third World within the Third World to whom "society is deaf and dumb and blind."[3]

The magnitude of their problems is almost incomprehensible: more than 350 million of the world's 500 million physically and mentally disabled people out of reach and out of help. How can we conceive what it means that more people than live in Canada, Mexico and the United States of America combined presently receive no attention to the physical and mental impairment which needlessly limit their lives.

If we were to add to this number the people closest to these disabled individuals, their immediate family members and dearest friends, people whose lives are intimately and inextricably altered by the presence of serious disability in their midst, we would be thinking about the entire population of the Western Hempisphere in need of help.[4]

The Industrialized World, with its varying national systems for social, political and economic organization, has never pretended to have solved all aspects of living with disability for the quarter of the world's people within its confines.[5] Organizations of disabled people and their families are increasingly vocal in making known their assessment of the shortcomings of existing programs and policies, not the least of which is the absence of disabled people themselves from the process of formulating and developing such programs and policies. The variety of issues is well known:

-the availability of existing systems to all segments of the physically and mentally disabled population;
-the equity of these systems.
-the kinds and extent of services and benefits available;
-the relative emphasis on different components within the available service and benefit systems including particularly the emphasis on fostering or inhibiting independent life activity;
-the relative status and lifesytle of disabled people as compared to other members of their communities;
-and as a result of all these factors, the ability of disabled people along with all other members of their communities to take an active part in the life of society.

These are the types of issues being analyzed by the privileged few.

Inflation, recession, decreasing numbers of productive age workers, increasing numbers of older people drawing upon reserves of social insurance benefits, and growing awareness of the limits to economic growth, all ensure that the costs and benefits of services and systems to rehabilitate and sustain disabled people will be subject to ever greater scrutiny in the industrialized world during the decade of the 80's. Disabled people, their families, and all concerned members of society will necessarily have to unite their efforts to retain the gains already made while improving conditions for the future.

The Fourth World. Conditions of life in the "Fourth World" are less well recognized. The "Fourth World" is theoretically composed of those groups of people within all industrial nations who still live in a condition of severe poverty: people without sufficient food, without a secure home, without social status or esteem; people whose children learn in school to be humiliated and to be confused; children who are separated from the care of their natural parents; families judged to have lower moral, ethical or work standards than others in the community. From generation to generation, the people of the "Fourth World" tend to live in extreme poverty and at the bottom of the social scale. They are joined by others who are poor and culturally vulnerable such as migrant workers, new immigrants, excluded racial and ethnic groups. Within the European Economic Community, the Fourth World population has been estimated to be 4-5 percent of the people.[6] In N orth America, families of the Fourth World are often described as those with "low incomes." They are entitled, as a result, to a variety of forms of social assistance including coupons for the purchase of food, public health services, and social welfare payments. Unfortunately these benefits cannot deal with many of the perpetuating factors which exist to keep them locked within a cycle of dependence and poverty, and which endow them with a permanent, albeit unwanted citizenship in the Fourth World.

One voluntary organization in the United States has launched a campaign to inform the public about the link between poverty and disability. It says: "You don't have to be poor to have a mentally retarded child...poverty just gives

*** United Nations International Children's Emergency Fund.**

you a good headstart."[7] The National Association for Retarded Citizens goes on to describe the many factors which account for the higher incidence of mental retardation in poverty areas; malnutrition, poor medical care, cultural deprivation, health hazards, isolation from existing services. In its study for UNICEF, Rehabilitation International found that the inter-relationships between childhood disability and poverty are far more entensive and damaging than had been anticipated. The principal causes of disability in developing areas --inadequate nutrition, difficulties at birth, diseases, infections and accidents -- all are far more likely to affect the ignorant and the impoverished, those people who live without access to the most fundamental human services.

The risk of physical or mental impairment is thus much greater for the children of the impoverished. The birth of an impaired child, or the onset of disability in the family, by placing an additional demand on the family's already limited resources, has the unfortunate consequences of thrusting the family into even deeper poverty. The *RI/UNICEF study documented this fact in every region of the developing world. It has been verified repeatedly through research studies of the relative socio-economic status of disabled people and their families in more industrially developed areas. The implications of disability for families of the Fourth World are serious and real; they simply are not well enough known or understood.

II. The Socio-Economic Impacts of Disability

The United Nations (UN) study on **The Social and Economic Implications of Investments in Rehabilitation for Disabled People** concludes: "Disability will create a cost to society regardless of whether or not rehabilitation services exist. In fact, it appears that the more a society recognize these costs, and the more it attempts to ameliorate them through the provision of adequate disability prevention and rehabilitation services, the greater is the overall economic return that may be expected."[8]

A subsequent United Nations expert group[9] review of the study defined the multiple impacts disability may have upon different sectors of society and upon the nation as a whole, particularly in developing regions.

From the perspective of the individual and the family, disability may result in:

-Increased personal stress, both physical and emotional for marital partners and family members;
-Reduced ability to care for children or to undertake household tasks;
-Reduced time and energy available to members of the household and friends for work activity;
-Reduced social contribution and interaction of the individual, loss of friends, loss of educational opportunity;
-Reduced status of the family in the community, possibly making it the focus of fear or aversion in the local community.

The U.N. expert meeting concluded that in relation to implications for the work force, the labor market and income distribution in any nation:

"Disability will often lead to poverty or disruptive change in economic status for the disabled individual and his or her family. The effect on the distribution of income between households may be doubly adverse. The disabled person loses his or her income; the need to care for the disabled person may cause some other family member to stop working...

Disability can have serious financial implication for industry in terms of labor turnover and the retraining of new workers...

Disability may force people to remain idle and dependent. In countries with unemployment, the disabled may be relegated to reserve labor force status to be employed only when demand for labor is very high and to be laid off as soon as demand falls...

The costs of disability will be greatest where nations are in need of an increased active work force. Disability may reduce the active work force capability of a nation with a resultant effect on the support of the social benefit system. In some industrialized nations with aging populations and increased numbers of disabled persons, there is a trend towards reduced numbers of active workers supporting each recipient of social benefits. In other nations, the population in younger age groups is increasing. These trends have long-term effects on the financial bases of social benefit schemes...

In developing countries with normally low rates of employment, planners may erroneously conclude that it is unnecessary to include the disabled in their labor policy."

Any intervention to reduce the impact and consequent cost of disability may be assessed from the perspective of the individual directly concerned and his or her family, of the particular institutions or program offering services or assistance to them and of society or the nation as a whole.[10] If it is assumed that society as a whole does not neglect the disabled and that it is taking actions to provide people with disabilities with a socially acceptable level of living, then the sum of all categories of benefits from rehabilitation service provision will far exceed the costs of such service provision. A nation may regain the costs of its rehabilitation services through such benefits as the production output of disabled workers retrained for employment, the return of tax income, the reduction of administrative costs for

*** (RI) Rehabilitation International**

transfer payments such as pensions and other benefits, and the reduction in health care costs. This does not even begin to take into account the human and social gains of rehabilitation activity, which are presently immeasureable in monetary terms.

The United Nations expert group and other international reviews of the subject have concluded that a considerable amount of information is needed before we will have a complete understanding of the socio-economic impact of disability. Some of the most important areas in which basic information is lacking include:

-assessment of the non-monetary outcomes of rehabilitation interventions;
-the inter-relationships between various components of the disability prevention and rehabilitation process, including especially the inter-relationship of factors such as labor market policies, disability benefit schemes, the availability of relevant services, and particular population needs;
-the effects on costs and outcomes of providing rehabilitation and disability prevention services more economically.

Nonetheless, despite the absence of much needed information, and indeed recognizing that to obtain the needed information, cross-nationally will require a substantial and long-term commitment of resources, the United Nations expert group and others affirmed that:

"We have been too cautious in evaluating the full impact of disability and rehabilitation service provision in economic terms...A greater understanding of these forces will serve to strengthen governmental (determination) to implement the most essential humanitarian principles.[11]

III. The Range of Rehabilitation Services

A broad range of rehabilitative measures have been evolved in the industrialized world over the last four decades. They have been designed to accomplish for each disabled individual the ultimate objective of "attainment of the optimum level of independent functioning and a return to active community life."

The types of services possible can be grouped into the following broad categories:

-Medical care and treatment;
-Therapeutic measures such as those provided by physical therapists, occupational therapists, speech therapists, psychologists, and others;
-Training in self-care activities including mobility, communication and daily living skills;
-Provision of technical aids and other assistive devices, prostheses and/or;
-Education, including adapted and special educational measures;
-Vocational assessment; training and placement;
-Social guidance and assistance.

When these types of special services and measures are provided within the services available to the population as a whole many adaptations of the general services may be needed. Thus, education of disabled children within the normal educational system may require significant modification of the educational program and the physical environment as well as development of necessary support services for teachers and students alike. In order for disabled adults to have the same access to higher educational opportunities as others in their nations, similar modifications may be needed.

Vocational services for disabled people should be carried out as far as possible within the context of services such as vocational training and labor market placement available to the population as a whole. Such services are generally offered to those disabled young people and adults who have a reasonable likelihood of engaging in productive activity. Experience in many nations, under varying economic and labor market conditions, has demonstrated repeatedly that people with even the most severe physical and mental limitations are capable of engaging in productive activity that can contribute to the national economy if services are organized and provided for them in a manner which capitalizes upon their abilities rather than their limitations. Similarly, selective placement of disabled people in employment, when necessary, should be based upon matching the abilities of the person with the requirements of the job and making any special adaptations of equipment, or work places necessary to facilitate the process. Measures may be taken to encourage employers to hire and train disabled workers. This takes on special importance during periods of economic depression under-employment, and limitation of employment opportunities. Special measures may be needed to assure that disabled people are employed along with all other qualified and available workers.

Some of the measures which may be taken, and which have been utilized in different parts of the world to create and widen employment opportunities for disabled people in both rural and urban areas include:

-incentive-oriented employment quota schemes;
-reserved or designated employment;
-provision of loans or grants for development of small businesses
-grants of contracts or priority production rights to workshops and cooperatives of disabled people;
-tax concessions and other financial assistance to adapt the workplace for disabled workers.

Trade unions and organizations of employers can cooperate in this process and in the development of the measures most suitable to the nation. They can also be involved in development of measures for those disabled people who are

unable to engage in competitive employment. A variety of sheltered and semi-sheltered conditions are possible within ordinary work enterprises or apart from them, when needed, for those who are homebound or otherwise out-of-reach.

Social assistance and social insurance benefits may be offered in a variety of forms and based upon a variety of entitlement criteria. The mix of the various forms of benefits and compensation, such as those for workers injured on the job, for the war-disabled, for the elderly retired from the workforce, for victims of accidents or other forms of negligence, for persons with certain types of disability singled out for special attention, grows out of the historical development, economic practice, economic status and social conventions of the different nations. Increasingly the right of disabled people "to economic and social security and to a decent level of living"[12] is being recognized. Whether social, benefits are offered as a form of social assistance or as a result of prior entitlement through a scheme of social security, social insurance or worker's compensation, it is now more likely that funds provided to disabled people and their families will be recognized as an essential right rather than as an act of charity.

Development of positive attitudes concerning the contribution of disabled people to social life is another objective of all rehabilitation activity. Many rehabilitation-related services build-in to their programs activities for education of the general public and specific professional groups. Some organizations of disabled people have adopted the responsibility to create positive attitude change as one of their principal objectives. Their target may be rehabilitation workers as much as others within society who affect how disabled people perceive themselves and their capabilities.

Educational efforts to raise community consciousness of the potential of disabled people to contribute, along with all others, to economic, political, and social life must be based upon realistic images of disabled people. They should show the skills, talents, feelings and limitations that people with disabilities share in common with all other people. They should avoid stereotyped or charitable interpretations. As far as possible, disabled people should be involved as trainers, teachers and public educators. Members of the community need to be made aware of the universal needs, and also the special needs, of people with different types of physical, mental and sensory impairment.

Public education should be a long-term effort based on appropriate communication techniques. It is a form of "public rehabilitation". Like rehabilitation, it must be started early, preferably within programs for young children and at school. And, it must be continuous. A considerable commitment of effort and resources will be necessary before attitudes which are socially handicapping for disabled people can be eradicated in today's world, and thus, prevented in the world of tomorrow.

Social planners have long recognized that it is more feasible to change the behavior of people than it is to change their attitudes. One of the principal social tools available to regulate behavior change is legislation. Some of the important, internationally agreed concepts concerning legislative measures and the rehabilitation process are:

-that provisions for the rehabilitation and welfare of disabled people should as far as possible be integrated within the general legislative provisions of each nation;

-that Governmental authorities should be obliged to consult with organizations of and for disabled people and with professionals involved in the rehabilitation process, in the preparation, planning and implementation of legislation.

-that each nation should have a long-range national plan for disability prevention and rehabilitation which is compatible with and included within any national plan for socio-economic development.

The Rehabilitation International Second International Conference on Legislation Concerning the Disabled, Manila, 1978, specifically recommended that legislation should:[13]

"Include adequate provision for the financing of comprehensive rehabilitation services and other facilities needed by disabled persons;"

"Provide adequate funds and trained personnel to assure that the service delivery network includes facilities for the early identification and adequate assessment of disability;"

"Set up viable structures, create linkages, and provide adequate resources to insure and facilitate the delivery of services for the disabled in rural areas;"

"Provide that all public and private buildings are free of architectural barriers, and that public transportation and recreational and social facilities used by the public be fully accessible to disabled persons."

The Conference urged every developing country to "legislate before 1981, the International Year of Disabled Persons, to ensure the right of access to and the provision of educational, medical, social and vocational services needed to enable all disabled persons to enjoy their rights and develop their potentials." It further recommended that each developing country establish by legislation a national council for the welfare and rehabilitation of disabled people charged with development of a national rehabilitation plan, and with the continuing evaluation of the services provided.

IV. The Underlying Principles

Some of the principles underlying application of measures and services associated with the rehabilitation process may be summarized as follows:[14]

1. Efforts to prevent disability should be a part of all national and community programs including those for primary health care, education, nutrition, family planning, social welfare, environmental sanitation, pollution control, work and traffic safety, and maternal and birth care.

2. Disability prevention and rehabilitation constitute a continuum of effort. Prevention of impairment is only the first phase of the full range of actions which can be taken to reduce the costs of disability to society. Once impairment has occurred, measures exist to prevent the development of permanent functional limitation or to reduce as far as possible its limiting consequences. And when functional limitation is present, an additional spectrum of actions is possible to prevent the community from unnecessarily separating or stigmatizing disabled people through conditions in the physical and social environments. Prevention of impairment, reduction of functional limitation, and elimination of social handicapping are three inter-related and inter-dependent elements of the prevention/rehabilitation process. The history of a six year old child I met recently in a village in Southeast Asia may illustrate some of these links:

> *Tina lives with her parents, brothers and sisters in a two room hut in a town in good communication with the rest of her home country. The town has excellent primary health services, basic education, roads to reach the capital city and full availability of goods and food. The town, in fact, is one of a few in the country with a small center for rehabilitation of disabled people and training of field workers in this specialty. Tina's family is poor in relation to others in the community. Her home is one of a small number without electricity. Three years ago when the family lantern overturned in the house, Tina was burned seriously on her left leg. She now has extensive scar tissue near her knee joint which keeps her leg permanently crooked at about a 30 degree angle off the ground. Tina can move about only by hopping on her good leg. She doesn't do this very much since her family has not permitted her to leave home since the accident. They do not consider that she should attend school, play with other children in the community play area, or move about the community in any way. Despite the fact that the local clinic and rehabilitation facility are within walking distance of the family home, Tina's parents have never considered nor been advised by their friends or workers in the community to take this child for treatment. They believe that nothing can be done to improve her lot in life.*
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> *In the three years since the accident, Tina has evolved from an outgoing and bright child into a withdrawn young girl who is afraid to leave her home and associate with others. We can see in her situation a full range of preventable problems: an impairment from burning which resulted from faulty placement of a lantern in the home; social isolation which resulted from ignorance and outdated attitudes on the part of both family and community members; increasing mobility limitations for the child as a result of failure to use the restorative measures available in the community health facility; and failure to provide the child with a basic education regardless of her mobility problems so that she could at the very least develop her other capabilities. What started as a preventable and relatively uncomplicated impairment, grew for this child into a multiple and socially handicapping condition which will completely overshadow her potential for a productive life.*[15]

3. Early detection and intervention is essential for maximum reduction of functional limitations as a result of physical or mental impairment. Groups of people known to be a risk of impairment must be identified and advised early -- works in certain hazardous occupations; women with a history of difficulty in childbearing; families with consanguineous marriages or having a history of genetic disorder; individuals exposed to certain types of infectious diseases, particularly if exposure occurs during pregnancy. A registry or some other system may be necessary to identify disabled children and adults early in life, based on principles of confidentiality, voluntary participation, and non-discrimination.

4. Rehabilitation measures must be relevant to the needs of the individual and his/her family members, taking into account their existing resources, social and economic situation, and cultural values. This means that the disabled person and his/her family members must be involved in the planning, conduct and evaluation of the rehabilitation effort. The forms of support provided should help the family to cope as far as possible with any disability-related problems at home and within the local community. Measures which might separate the disabled child or adult from ordinary family life should be avoided to the greatest extent possible. In addition, there must be a means to coordinate for the family all of the services which it receives related to the disability of one or several of its members.

5. The community must be the focus of all rehabilitation efforts. This is a corollary to the fact that rehabilitation measures should meet the needs of individuals and their families. It would require that any of the special services needed by disabled people be available, to the greatest extent possible, at community level. At the same time, the basic educational, health, employment, recreation and social services of the community should be useable to the maximum extent possible by disabled people. This extension of services should encompass rural as well as urban locales, and they should be appropriate to the lifestyle of the community.

6. Rehabilitation services should be available to all people in need of them, on the basis of social equity. They should be provided without discrimination because of age, sex, financial capability, ethnic or racial background. The

type, cause, severity and/or prognosis for any impairment or condition should not serve as a basis for exclusion for needed assistance.

7. Rehabilitation measures should be provided in as economical a manner as possible. This may require development of simplified technologies which are not dependent upon costly, often imported, raw materials and equipment. It may mean training of rehabilitation workers who can carry out multiple functions at the community level in harmony with local patterns of community organization, and it should result in the development of rehabilitation processes which are realistic in terms of available human and financial resources.

8. Measures to prevent and reduce disability should be integrated as far as possible with the existing structures of society. The ultimate objective of all rehabilitation efforts is the social integration of disabled people in community life. Integration of rehabilitation measures within the services generally available in the community is one means to this end. Rehabilitation measures should be made available to all levels of existing community services including within program for: primary, secondary and higher education, basic and specialized health care; vocational training and placement in work; social service and social security, public education through the mass media. Rehabilitation measures should be provided, to the greatest degree possible, through such community systems. Only when necessary for accomplishment of discrete and more specialized objectives should they be provided through services apart from those available to the community as a whole.

9. People with different types of disabilities need different types of services and adaptations in the community. The measures provided for integration of disabled people must take into account the differing needs of people with differing disabilities.

10. Rehabilitation measures must be provided in a pattern which is continuous, coordinated and comprehensive. Efforts to prevent impairment and to reduce disabling and handicapping must form a continuous process in order to be effective. Since the components of the process are inter-dependent, the success of each intervention is hinged upon the availability and outcome of every other intervention. Campaigns to reduce impairments from traffic accidents or infectious diseases during one period of time will be rendered useless if they are not carried over during a longer period of time. Concentration on the problems of one group of disabled people, perhaps spinal-cord injured war veterans or thalidomide victims, to the exclusion of other equally seriously impaired people whose needs may be less visible or politically expedient can result in the development of unbalanced specialized services and systems. Additionally, since the rehabilitation process may encompass medical, social, and vocational measures in order to be effective, it follows that an adequate system for coordination is needed among all of the components and the different services they entail. The services provided may be from both governmental and voluntary sources. Coordination may thus be needed at the level of the individual and the family, at the level of the community, and at the highest levels of national policy formulation.

11. People must be trained to participate in the process of disability prevention and rehabilitation. This could include a far greater segment of the population than is traditionally associated with rehabilitation activity if the principles of integration and community-level focus of effort are to be attained. The basic facts about the causes of disability, the possibilities for rehabilitation, and the active role that disabled people can and should take in societal life should be made known to all members of the community, particularly to those people whose life work is central to the shaping of other people's lives: teachers, physicians and all other levels of health service workers; members of the clergy, social workers, and all other planners of human services. There must also be an increase in the number of people trained to directly provide rehabilitation services, with emphasis place on expanding knowledge, capabilities and responsibilities of service providers already at work in the community.

12. Disabled people and their families should be provided with the financial means to cope with the additional costs of disability. These costs may result from the need to purchase special services, technical devices or assistance necessary for functioning within the community. They may occur as a result of the need to overcome physical barriers within the community. They may occur as a result of the need to overcome physical barriers within the community that have not yet been eliminated, such as those found in housing, transportation, recreation and at the workplace. Existing schemes of social insurance, social security and social assistance may be used to offset the extra costs of disability to the individual and the family. They may also be used to provide the disabled person and family with an income when productive work at an economically viable level is not possible as a consequence of disability. Existing systems of social support should be examined to be certain that they do not exclude or discriminate against disabled people and their families. At the same time, provisions for financial assistance should offer incentives for rehabilitation and for attainment of the highest possible level of independent functioning for each person.[16]

V. Translating the Principles into a Larger Reality

It is a virtual certainty that no nation in the world has developed systems of rehabilitation accessible to all of its disabled citizens which are fully based upon the aforementioned principles of integration, completeness and continuity. It is a fact that no nation has succeeded in preventing all of the disability which can be prevented. We know that the principles enjoy general acceptance internationally based upon recommendations of recent regional and international conclaves, most recently the extensive consultations and reviews leading up to discussions at the Rehabilitation Inter-

national 14th World Congress in Winnipeg, Canada, of a Charter for the 80's. Several thousand participants from more than 75 nations took part in these discussions. Some nations admittedly are closer than others to attainment of the fundamental goals but all can benefit from an expanded effort to translate the underlying principles into a larger reality.

The magnitude of the problem, alone, dictates the importance of seeking more imaginative solutions in the future: less than one-quarter of the world's disabled people in reach of and receiving adequate rehabilitation assistance; more than two-thirds out of reach of such help, the majority living in rural areas within developing nations.

These are some of the possible avenues for future development.

Expanding the Manpower Base

The World Health Organization once cited an example of the implications of expanding rehabilitation services in developing nations on the basis of the conventional pattern of service delivery in a highly industrialized nation.[17] A plan was established to set up a rehabilitation institute in the capital city of a country in Africa. It was then recommended that the services be extended through establishment of similar institutes in the second largest city, then in the third and so on. Manpower needs in 11 different occupations to deliver the standard services were calculated. It was projected on this basis that if the entire health budget for the country were utilized solely for rehabilitation services, it would take 60 years to develop the necessary manpower and about 200 years to provide the desired amount of care to the population in need of it at that time!

In fact, few nations appear likely to have the resources to train and employ full quotas of what has been considered to be the optimal number and diversity of rehabilitation workers. More than 10 years ago, a Rehabilitation International expert group discussed the possiblity for development of different levels of rehabilitation workers under conditions of differing available resources.[18] Concepts for using lesser trained auxiliary workers in the community as a source of identification and referral were reviewed as one means to ensure broader outreach and better utilization of existing programs. Other levels of auxiliary personnel in provision of medical rehabilitation, prosthetics and orthotics services, social services, vocational services and special education were also considered. Since then, a number of developing nations have begun to train people who function in some way as community rehabilitation aides or as multi-disciplinary rehabilitation workers. A recent experimental project of the Pan American Health Organization in rural villages in Mexico is finding that community health assistants can effectively help, either through direct assistance or referral, more than 75 percent of the disabled people in some communities. This permits the smaller number of rehabilitation specialists to multiply the assistance they are trained to give.

Another important source of people to augment efforts to prevent disability and rehabilitate those already impaired lies within each community and its base of people who help other people. The base is very broad: community and business leaders engaged in public service, professional human service providers--teachers, health service workers, social workers, family planning counselors and day care center staff, the religious establishment of lay and clerical workers, the providers of human services who work outside of recognized professional regimes-healers, local birth attendants, shamans and other visionaries. These are the people who community members in distress at the unexpected occurence of disability are most likely to turn to for advise and guidance. These same people are as ignorant as any others in their community of the causes of disability, its prevention and potential for rehabilitation. Unless they are given the facts, through generic training programs such as those for all teachers, nurses, physicians and social workers, and through non-formal and indirect programs of public education, they will never understand the positive role that they might have in shaping the lives of the disabled members of their communities. Too often they serve as the perpetrators of superstition and myth rather than as the helpers that they could be. The precious knowledge and experience available to those individuals who have been trained in rehabilitation specialties remains a personal fief restricted to use by the select few in their communities who by reason of geography, wealth or social class may have access to them.

Openness to New Roles

Just as it is difficult to alter deeply held sterotypes as to the roots of disability and the capabilities of disabled people, it is difficult to change the image that rehabilitation professionals may have of the utility of their services or of their role in the rehabilitation process. To reach greater numbers of people with disabilities, it may be important for specialists to give greater attention to servicing as catalysts and motivators for the work of others: disabled people themselves, family members, concerned members of the community. This might entail a basic restructuring of the services provided, the equipment used, the locales in which services are offered and their time frame. An experimental project to train unemployed high school leavers in Jamaica in early identification and stimulation of developmental delayed children in slums and rural communities demonstrated that these young poeple could make a significant improvement in the lives of the families they served by training the family members to work with the children at home. They were not terribly concerned as to whether the family member was the natural mother, a grandparent, an elder sister or brother, or simply a consistently helpful neighbor. In very simple ways, they were able to help the people most directly concerned to improve the lives of the children affected and their own lives at the same time. The small number of professionals involved found their greatest strength to be in the liberation of the resources of others.

Simplified Methods

Disability and rehabilitation need to be "demystified" if we are to succeed in making more people in the coming decades a part of the solution and not of the problem. While the first forty years of the development of rehabilitation techniques and theories has been devoted to finding and applying technical solutions to the limitations imposed by impairment on the relatively select few, the next ten, twenty or thirty years may be devoted to finding and applying methods which maximize the involvement of the many. Guidelines are needed which will help all parents to help all of their children to develop and grow, including those they learn to recognize as developmentally delayed. It is pitiful to see or to have to estimate how many disabled children in the world today are being denied the fundamental stimulation that they, like all other children, need to grow including food, social stimulation, and space within which to move, because their families have never been provided with simple information about the causes and effects of their impairments. Is their any acceptable explanation of the fact that today, even in countries with the most sophisticated systems of rehabilitation imaginable, we cannot find a single example of a simple series of diagnostic steps a family might take to assess whether or not one of its members may be suffering from impairment? In the industrially developed world, the detection pattern involved has always entailed referral to a specialist despite the fact that it is the family which has the earliest and the closest familiarity with the problems of disability.

Focus on the Family

Mr. Alf Morris, of the United Kingdom, the world's first Minister for the Disabled, has said: "There is no such thing as a disabled person; there is only a disabled family." This is the ultimate recognition that the most important impact of disability will be on the family as a whole and the most important resource for dealing with the problem will also be within it. It is the family which adjusts to the demands upon each of its members and manages its time and resources accordingly to cope with the additional responsibilities imposed by disability, whether it be the problem of the growing child, the mother or father, an elderly grandparent or other relative. It is well known that the family can provide many forms of care at home more economically and more effectively than institutions.[19] It is also clear that the role of the family in shaping the self-image of the disabled person, child or adult, is pivotal. There is an explosion around the world of programs to draw upon the resources of the family and to support it in coping with disability: Parent-to-Parent programs, child-to-child, action groups and respite care, schemes for home help at any time of day or night dictated by the need that arises rather than by bureaucratic schedule. Hopefully more such programs will be forthcoming with an emphasis on programs that help the family to provide therapeutic activities at home; programs that use the materials available at home as the basis for assistive devices and equipment; programs that inform the family and make it a capable participant in the rehabilitation process.

Appropriate Technology

The technology of rehabilitation today is, unfortunately, not designed for use by the majority of disabled people in most parts of the world. When it is available it is often costly, dependent upon external energy sources including electricity, difficult to transport and assemble, reliant upon special component parts and people trained in their use and difficult to maintain. As a result of all of these factors, rehabilitation technology is virtually inaccessible to most people in the world. The technology is frequently also inappropriate culturally and climatically.[20] There is considerable irony in visiting a program for blind youth in rural Asia to see patient effort devoted to training these young people to weave "welcome mats" in a nation where few will ever read English nor place any value on wiping ones shoes at the door. (If you do have shoes in such circumstances you should know better than to soil the interior of the home by wearing them inside.)

There is a long list of used and donated equipment shipped around the world, with the best of intentions, only to be locked away and out of use because of a lack of parts or servicing. There is also a long list of people who were trained in specialized procedures they could never hope to use in their home countries. But there is another list under development now which will show the ingenuity of rehabilitation specialists, village workers, and family members in responding to the needs of disabled people with local resources and materials. The Partners of the Americas' rehabilitation program has interested IBM*, the giant of sophisticated technology, in supporting its collection of information on technologies effective under local community conditions. The resource catalog which results will surely be of the greatest utility. An experimental World Health Organization program to evaluate training manuals for community workers in rehabilitation using appropriate technolgy is also underway and should yield important results.

Appropriate technology is not always simple or labor intensive, although these can be some of the criteria. A researcher in England has found a way to use a highly sophisticated edible white powder to mold assistive grips for everyday implements that can then be used by arthritic, cerebral palsied, and other physically impaired people to function more independently. The technology is quite sophisticated; its application, in rural villages using a bit of water and the time of anyone interested to learn how to do the job in a few hours, is quite simple. The point, of course, is that only with technology appropriate to the situation will it be possible for family and community members to contribute to the process of rehabilitating more disabled people locally.

* International Business Machines

A parallel development on the regional level worth mentioning in this context is known as TCDC (Technical Cooperation Among Developing Countries). This is an outgowth of recognition among third world nations that many of the solutions for their problems will come from the techniques and approaches that have been developed in circumstances similar to their own, rather than from techniques grafted onto a resistant body from outside.

Reaching the Unreached

One of the direct results of the RI/UNICEF study on the situation of handicapped children in the developing world was a program in the Philippines called "Reaching the Unreached." The project is in its first year and it is based on recognition of the fact that most of the disabled children in that country will simply never be seen at local services for children after their birth. Most likely, they will be kept out of public sight within the sheltered and loving care of their families. They will not attend school nor go to the health center, nor play with other children in their community day-care center, nor even attend community festivities. The purpose of the project is to reach families at home, to assess any problems their children may be having, and to help them to help their children to grow in the best possible way. The project places a few rehabilitation workers in the community, works through existing community development activities and emphasizes measures which strengthen the capacity of the community to help its own members. "Reaching the Unreached" works together with a unique program to help families in the Philippines to stimulate the intellectual growth of their children through improved nutrition, early stimulation, socialization, and learning games. The objectives of this program for "Mental Feeding" complement well those of the program to reach and help disabled children. Both programs exemplify an active effort to find disability early, to intervene early and appropriately in terms of the community, and to produce an improvement in the quality of life for all who are directly affected. It is a trend which moves far from the traditional and passive concept of rehabilitation as a service available to the public and to be drawn upon by it. The active outreach approach recognizes that traditional stereotypes and economic realities may be making it impossible for those most in need of help to ever avail themselves of even such services as do exist. It also furthers the dissemination of information about disability causation which is of such great importance to efforts to reduce the problem in the future.

Potential Areas for Research

All of the experimental approaches cited above could be useful subjects of research analysis: e.g. the functions and effectivity of community rehabilitation workers; the effectiveness of measures to strengthen the capability of families to deal with disability; the range of technologies appropriate under differing conditions of material and manpower resources; the potential of simple measures to screen for and detect disability.

Some of the other areas which are little understood and could be fruitful and could be fruitfully examined from cross-national perspectives include:

Differing bases for allocating resources to differing components of the disability prevention/rehabilitation process; i.e., the relative weight in different nations on spending for and priority of disability benefits schemes, direct rehabilitation services; and labor market and social policies which affect disabled people. The effectiveness of varying patterns of mixing these components at the levels of the individual, the family, the service providing institutions and for society as a whole could be examined.

Measurement of the non-monetary outcomes of rehabilitation service provision, particularly in terms of the effects on those individuals directly affected, their family members, and others in the community. Such outcomes may involve changes in the management of time, changes in social behavior, changes in emotional well-being and potential for productivity. The capability of varying patterns of non-monetary gains could be compared.

The effects of disability on the active work force of a nation and on the base for maintenance of systems of social benefits; the varying labor market policies used by different nations to deal with these effects and their relative effectivity.

The effectivity of various measures to integrate services for disabled people within general systems of eductional, medical, vocational and social service for the community as a whole; the optimum balance between general and special services under differing conditions of economic and social development.

The implications of depending upon family, private, governmental and/or voluntary organization initiatives in the organization and delivery of rehabilitation services; analysis from the perspectives of cost-effectiveness as well as adequacy of outcomes for the individuals and families concerned.

Most of the comparative research studies which could be undertaken in subjects of these types would be difficult to develop methodologies for and to define. They would require considerable investment of funds, people and time over the next decade to produce useable comparative data. In some ways the question is not whether such research is affordable but rather whether we can afford to go on without it and without making a clearer delineation of how the varying elements of the rehabilitation process interact to create a coherent and effective policy for service provision and support.

The varied approaches I have cited possibly represent the beginning of some new ways of looking at the problems of providing disability prevention and rehabilitation services in the future in a way which will come to grips with the

harsh reality and the scope of the problem. They may be of relevance in any of the worlds within the world where disabiity remains an unsolved problem. They are intended to be useful in any circumstances where resources are limited: resources of people, of material, and of money. Limitation of resources, like disability, is a universal problem. There cannot be an arbitrary division therefore, of methods which might be appropriate for the Third World, but not for the industrialized world, or vice versa. At the same time, out of the diversity of experience that characterizes the way that people cope with disability under different circumstances, this listing can only be a first step in a long process of examination, experimentation and review.

Mahatma Gandhi, the great sage of the Indian Subcontinent, aptly summarized the situation more than forty years ago when he said.

> *"The difference between what we do and what we could do would suffice to solve most of the world's problems."*[21]

I would hope that by helping planners to understand the important role of people with disabilities within the fabric of community life, we will increasingly add their strength to all other efforts to develop a world more habitable and hospitable to all of its people.

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Excerpts of Reviews and Comments

The following are excerpts of reviews, comments and questions raised by the Switzer Fellows. These are presented to further stimulate thinking as well as action as it relates to the content of the chapter by Susan Hammerman.

"Hammerman's paper reviews the major needs of the disabled throughout the world. As in the Marge and Acton papers, she emphasizes the importance of an increased focus on prevention of disability for the coming decades.

Ms. Hammerman points out the need to raise community consciousness about the potential of disabled people to contribute to society. It will be interesting to explore this recommendation in greater detail to determine ways in which this can be accomplished in third world countries. One would assume that it is extremely difficult to realize changes in culturally embedded views about health and health care. This is not to say that such views cannot be modified, but what is the current evidence about the effects of such efforts in developing countries?

The author's focus on the family as a major resource for better health delivery and therefore, better care for the disabled, is an important one which needs discussion at the Seminar. The use of the family raises the same question discussed above about increasing the community's consciousness concerning the potential contributions of the disabled. We are speaking again about the modification of established attitudes. We need to examine effective ways in which this can be done without causing major disruptions in the culture and mores of the society. In addition to effectiveness, it is essential that we seek low-cost and cost effective approaches, especially for developing countries. This is an area of research which is in need of further development."

--Michael Marge, Ed.D.

"This paper spells out in definitive terms policies and guidelines for the 80's. The review of problems facing the disabled in developed, developing and pre-developing countries is direct and to the point.

The problem of dependency is given a great deal of play in her review. The necessity of looking at population statistics in understanding what impedes growth of rehabilitation in poor countries and poverty areas is made meaningful. Her recommended measures for work with the disabled are excellent."

--James S. Peters, II, Ph.D.

"**How,** in a practical way, do we expand the manpower base?

Dr. Hammerman identifies many potential sources of manpower -- auxiliary personnel, community and business leaders, professional human service providers, etc. This is a good beginning list to which seminar participants may wish to add, e.g. disabled people themselves. More importantly we need to identify some strategies for reaching the manpower base and providing them with the necessary tools to be effective. One way to think of this issue is to perceive it as an information dissemination issue. The models described in the Pan/Duncan paper may be a good starting point in formulating strategies for expanding the manpower base."

--Elizabeth Pan, Ph.D.

"In the developing countries, the rehabilitation services that do exist reach only a tiny fraction of those in need, and disability prevention efforts are too often non-existent. Susan Hammerman's paper perhaps best captures the magnitude of the problem: 'By the year 2000, almost five billion of the world's (estimated) six billion people will live in developing nations; more than one-third of them will be children under the age of 15 years,' and '...approximately one-third of all children in the developing world live in rural areas completely beyond the reach of health and social services.' "

New approaches to the problem of disability prevention, rehabilitation, and I would add integration, full participation and equality are clearly required in developing countries. Hammerman cited the WHO example of the implications of building rehabilitation services in developing nations on the basis of conventional patterns of service delivery -- it would take 60 years, if the entire health budget were utilized solely for rehabilitation services, to develop the necessary manpower, and 200 years to provide care to the population in need at that time in just one country in Africa!"

--Robert B. Ransom

"The major part of the paper focuses on needs, potential and values with which there is a broad base of agreement among progressive thinkers.

Her emphasis on more utilitarian perspectives to work force deployment and simplified technology are issues which should receive further consideration at the Seminar.

The ILSMH* has adopted the concept of a "Manpower Model" to personnel preparation, deployment and utilization which provides a framework for he concept of delegated function referred to in the paper. Her paper poses the problem of how to implement the concepts she advances in developing and developed nations. Some experiments have been tried in this regard which can be discussed in the Seminar.

"The paper complements Acton's in relation to the question of how to realize more of what is possible. She quotes Ghandi: 'The difference between what we do and what we could do would suffice to solve most of the world's problems.' The Seminar's challenge is to delineate the **action** options which can be effectively implemented."

**International League of Societies of the Mentally Handicapped*

--G. Allan Roeher, Ph.D.

Summary of Recommendations

The following is a brief summary of the recommendations and implications for action as developed by the Switzer Fellows as it relates to the topic of the third chapter. (The recorder was Dr. Jeanne Kenmore).

I. General Principles: The Framework for Policy

The group discussions on general principles for assurance of necessary services and support systems were based on, and in agreement with, the underlying principles set out in the Hammerman text. Foremost among these concepts is the right of disabled people to live, the right as is stated in the United Nations Declaration on the Rights of Disabled Persons "to enjoy a decent life, as normal and full as possible."

This means that all general systems of society designed with the needs of people in mind should equally be designed with the needs of disabled people, both children and adults, in mind. General service systems should be made available to and usable by disabled people and their families just as they are available to all other members of society. When the special needs of disabled people dictate the necessity of additional rehabilitative measures of the types described in the paper, such measures should in principle be provided in a manner which is integrated within the general service systems, within the community and at the level of the community.

The overwhelming dimensions of the worldwide problem of unresolved disability, and the limited resources available to deal with this problem in every community make it necessary to prioritize actions for disability prevention and rehabilitation. Priority should be accorded to those actions which conform to the international principles set out in the report. Most importantly, priority should be assigned to those activities which will result in the greatest good for the greatest number of disabled people, especially those people who are now reached the least and served the least.

Refocusing of priorities for international action in the fields of disability prevention and rehabilitation may require the channeling of present forms of assistance and activity into some new patterns such as those which are fundamentally designed:

to provide needed services more economically;
to involve more people in extending and expanding the process we call rehabilitation;
to involve those people most closely affected by the problems of disability, disabled people and their families, in the process of rehabilitation and "self-help."

II. Program Development

Historically all nations have experienced trials and errors in developing their programs to service people with handicaps. Policies and practices valid in the past may no longer be considered valid today. Mistakes, in fact, have been part of the process of learning how to best provide such services. When nations develop programs which are new to them, it would be well to learn about conditions under which similar programs were developed in other parts of the world, and to determine the relevance of various aspects of these programs, particularly from the perspectives of cultural and economic appropriateness. It may thereby be possible to avoid costly and/or ineffective methods, mistakes and waste.

While sharing basic principles and priorities in disability prevention and rehabilitation, the transfer of practices from one country to another, or between regions within one country, may not always be desirable. In light of the tremendous needs and lack of resources of developing countries, innovative, collaborative, community-based demonstration projects and programs should be encouraged.

National development plans of developing countries should reflect rehabilitation and disability prevention as an integral part of planning for education, public health, training, community - urban and rural-development . Any separately developed plans for the development of rehabilitation services must be included in the National Development Plan of a country, if implementation is to be assured.

III. Service Delivery

Meeting the special needs of handicapped people may be accomplished by individuals with a variety of backgrounds and qualifications. For example, service roles range from the villager with no formal education through all categories of personnel with various informal and formal training. It is important to decide in advance what knowledges, skills, abilities are absolutely necessary for the job and not to over or under train. As services reach greater numbers of disabled people in rural areas and slum sections in large cities, new occupations will be created calling for a variety of skills only some of which require long years of study.

Frequent contact with disabled individuals as their lives change because of age, environment, family situation or economic conditions is of fundamental value and importance in the development of service programs.

The rehabilitation community should encourage government and private agencies engaged in general human service delivery and development activitites to include handicapped persons as program participants and recipients.

IV. Training of Personnel

Many nations have knowledge and experience to offer one another. Person-to-person contact is probably the most effective way to share this information. National, regional, and even world-wide conferences offer this opportunity. Long-term training programs provide extended time for person-to-person communication to take place. When an institution or a country requests training for personnel, the trainees are often sent abroad and receive their education or training in another country. Upon return to their home country these people are expected to instigate programs, to train fellow citizens and to provide the leadership necessary for implementation and institutionalization of new ideas. One way of making the development process move more expeditiously is to invite consultants/experts from other countries to spend sufficient time in the host country so that greater numbers of persons in many occupations and professions may be trained. However, these consultants/experts must learn as much as possible about the local cultures, about the usual methods of instruction, about the acceptable procedures for bringing about change, and they must learn to work within that framework.

Long-term degree training programs conducted in other countries must be sensitive to the needs of students from different lands but basic professional academic standards should not be compromised. To do so is an injustice to the participants and their sponsors. It is also important to prepare students from other countries for their leadership responsibilities (policy making, program development, teaching) which they will face upon return to their home countries. Upon reentering their own cultures it is important that these people, who represent an important new national resource, make a committed effort to avoid becoming detached or isolated "elites." That is, they must remain in contact with the service personnel and the organizations who are dealing on a day-to-day basis with the countries' "real world" rehabilitation problems.

Short-term training programs conducted within the host country should focus on two groups.

1. Multidisciplinary rehabilitation personnel,
2. General human service workers, i.e., teachers, nurses, social workers, clergy.

The participants should also represent both professional and paraprofessional personnel.

V. Legislative Needs

General legislation which applies to all citizens of a country should not exclude the disabled. For example, if the law states that all children are entitled to a minimum of a specific number of years of education it should apply equally strongly to children with various disabilities.

In the past decades special legislation for handicapped people has tended to follow the development and implementation of service programs. Recently some countries have passed legislation designed to extend the disabled individual's rights to specific services. This has contributed to the improvement and the proliferation of services.

If the legislative "frontier" is too far in advance of present facilities and service programs and understanding, it has little impact or capacity for implementation. To be meaningful, there should be a reasonable relationship between the law and the readiness of people and the existing structures to act in accordance with the law.

SWITZER FELLOWS: Fellows here are, left to right, George Engstrom, Dr. Marceline E. Jaques, Dr. Jeanne Kenmore, Mercedese M. Miller and Susan Hammerman. Missing from the pictures are Fellows Bruce M. Curtis, Fred J. Krause, Robert Ruffner and Diane Woods.

Chapter Four
By Bruce M. Curtis

The Need For Full Integration Of Disabled Persons In Their Society

Summary Comments

This paper provides some exceptionally interesting insights into the problems that have accompanied the development or failure, of the integration of people with disabilities into the societies that make up the United States. Understandably, its emphasis is on problems rather than on successes, and it tends to focus on the role of organizations of people with disabilities in the integration process. One of the great unexamined phenomena in this area of human development is the substantial body of significantly disabled persons who, for whatever reasons, have managed integration to the extent that they no longer appear in our statistics. The question of whether organizations of people with disabiities and their proxies enhance or retard integration will be answered only by history, but it is certainly a defendable position to claim, in the light of the conspicuous lethargy of society as a whole towards the problems of those with disabilities, that those most affected must mobilize and act.

Understanding of these issues will benefit greatly from a collection of information and experience from countries other than the United States. In the context of the theme of the seminar it will be necessary to discuss these issues with reference to their international implications, especially as they are relevant to the situation in countries in the early stages of economic and social development. After all, that is where most of the people with disabilities live.

In the United States, the United Kingdom, Sweden, the Netherlands and other highly industrialized countries a large amount of money is spent on processes that are supposed to stimulate and augment integration. As the author points out, accomplishments in the U.S. has been meager -- and observable results in other developed countries is the same. How then do we advise other countries to plan their approaches to this problem?

The author raises questions about the concept of integration and with good reason. We assume that integration and full participation are everyone's goals. Are they? For people with disabilities? For people who are not described as disabled? This needs a hard analysis.

Comments by Norman Acton

Why We, The Severely Disabled, Wanted Integration

There have always been disabled people who have managed to be successful, and some who were not severely disabled, managed to pass or hide disabilities and lead successful lives. There were even severely disabled people who managed to get a job, raise a family, participate in their community and feel that their lives, while difficult, were still acceptable and enjoyable. Yet, a great many disabled people were not satisfied. With the advent of new medicine, medical techniques, and improved medical support services, large numbers of disabled people, especially at a young age, started participating more in the community. People disabled from birth, and those injured in their youth, were now finding themselves medically stable and wondering what to do with their lives.

Yet when we left the hospital, people in the community felt we didn't belong. When we tried to live on our own, the lack of families could keep us from succeeding. When we wanted to go to a library or a restaurant we couldn't get in. Even if we could enter a regular school or college, our future seemed like endless years of classes because no one would hire us.

In the late sixties, and at the beginning of the decade of the seventies, several disabled individuals were encouraged by the success of the student movement in the sixties, the draft movement, and the women's movement. With the success of the civil rights demonstrations to make demands and get results from governing bodies, we decided to try and get the same results for disable people. In these first few years - late '69, '70, '71 - severely disabled people began recognizing that they were not able to receive services in the community without a great deal of difficulty. Difficulties such as: locating a house (if they could afford one); being able to get into their local city hall, movie theatre, or restaurant; with physical barriers keeping them out. This was complicated by social service programs whose workers had no understanding of disability and it's concurrent problems. As an example, when a severely disabled person tried to get attendant care, the social worker who was trained to screen people out or limit services, would tell the disabled person s/he was not eligible for more than one or two hours a day of attendant care.

We learned that the only way to get the amount of hours of help we needed was to have a "dirty house," be unwashed for over two weeks and tell the social worker that you're going to have a bowel movement and it isn't safe for you to transfer to the toilet by yourself. At this point the social worker would panic and suggest that you could use more hours of attendant care.

This kind of problem and response was rampant under support services such as Social Security, Department of Rehabilitation, Aid to Families with Dependent Children and the County Department of Public Social Services to name only a few. Traditionally, these social workers had no training providing services to disabled people. They had no knowledge or sensitivity of our special problems and were, therefore, often insensitive to the needs of the disabled population. Often all of these community services, these and more, were not available to disabled people because the physically disabled had no means to physically get into the building. A services provider from one agency did not know how to how to interrelate with a service provider from another agency nor how to solve the multiple problems of independent living in a community. Disabled people needed a coordinated attack as opposed to an individualistic attack on the alieviation of their problems.

In addition to the needs for direct services in the community, there was a problem of forced dependency. Disabled people were kept out of the employment market because employers didn't feel they were productive enough; because of insurance companies' attitudes about disabled workers being greater risks for injury on the job and because of attitudes which said that the image of a good worker was a non-disabled worker. The employer might feel that anyone who had a disability essentially would keep the public from feeling comfortable and would interfere with services or sales to the public.

Dependency was also forced onto disabled people by the family being the sole economic means for maintaining a disabled person. This was reinforced since the disabled person was unlikely to get a job. The dependency on the family was not only acceptable by society in general, but was actively encouraged as a means to limit the financial obligation of the government and of the social service agencies. It was never discussed, or it was never considered what the effects on disabled people would be, with this kind of forced economic dependency.

Sometimes poverty became a way of life for disabled people. There was little opportunity for jobs, or when jobs were found they were low-paying jobs with no upward mobility. Not only the poverty of usually not having an opportunity for a job, but also the poverty of being government supported by financial assistance programs such as Aid to the Disabled (which eventually became Supplemental Security Income), led to feelings of hopelessness. These programs often were barely enough to pay for food and housing and were rarely enough to handle the additional needs of most people, such as transportation, clothes, electricity, recreation, etc., and these were considered luxuries. The amount of money for assistance would vary from state to state. Many states took the attitude that they should not add any more money to the basic federal grants. Therefore, you would have in many states, half as much being paid to disabled people as in other states even though in the highest paying states this was still barely a survival income.

The services, the dependency and the poverty were all manifestations of traditional responses, traditional attitudes toward disabled people, and stereotyped attitudes based on custom and historical practice. These stereotyped attitudes labeled disabled people as being essentially incapable of any kind of worth, value or benefit to the community; that they are only a necessary burden to the family or to the community. These attitudes lead to and maintained inequities, discrimination and the continued dependency of disabled people. Who could attempt to sum up the feelings of a young disabled person or even of an older disabled person?

In the sixties and the seventies, disabled people watching other discriminated groups making demands, organizing and having success in having those demands met, could sense the possiblity that life did not have to be the way they experienced it. Maybe there was even some hope for change and a better life to live. Even while these feelings were growing in response to other successful social movements, disabled people were basically isolated from all these social movements. In addition, these movements were not aware of or knowledgeable of the problems of disabled people even though disabled people could be considered members of these movements. This isolation of disabled people could best be pointed to in the lack of information about and the lack of inclusion of disabled people in these new and struggling social demands.

The isolation of disabled people was also from each other in that disability ran across all barriers of social positions, wealth, poverty, ethnic, geographical and educational attainment. There weren't any similarities between all these

disabled people except for the fact that each had a disability and having that disability had some effect on their lives. Their isolation was often not only one of information and opportunity, but commonly one of physical isolation. Many disabled people were isolated from other disabled people and from the community through physical barriers; through living in segregated facilities under close supervision; by families who would not allow their disabled family members to leave the house or participate in family events which could have been a means of community participation. Even to the outright isolating of disabled people by national policies that build large multiresidential buildings for "disabled only", or by warehousing the disabled in state institutions and state schools.

This was where disabled people found themselves in the late sixties and the beginning of the seventies, with an immense task of organizing, educating, advocating and demanding integration in the community with the hope of a new future of integration, equal rights and equal participation.

Who Were We?

The disabled people who felt the possibilities of change in their lives, who saw the new mechanisms that would include them in the community, who felt the possibility of organizing and directing large numbers of disabled people in the country, were primarily young disabled people. Of these young people, most in their twenties and thirties, some had indiviudual successes with becoming independent, some had little success with living independently, but they had disabled friends living independently for role models. These disabled people were often college educated because there wasn't much else to do, schooling was usally free. They were from white, middle class backgrounds with the values of the middle class. It seemed to them that success was possible for anyone who worked hard and tried to make the system work. They believed that everybody was equal and idealism could be a reality. Likewise, ambition and competitiveness were crucial to feel that they could succeed against overwhelming odds. We will see, I think, in the remaining part of this paper, that some of these values were what led to a lot of the problems we see today. All these efforts were to be directed at the system, trying to make the system work, trying to address the inequality and oppressive nature of the system. Basically we were trying to reform the system.

What Did We Learn To Do?

In trying to decide how to go about this undertaking, often personal experience in political organizing - city meetings, community development, schools, leadership positions, and other social movements such as the Black, Chicano, anti-draft, anti-war and environmental, served as training grounds.

A few individuals tried to make changes based on their own particular problems and tried to set a precedent to make things better, not only for themselves, but for other people. There were those who tried to start organizing disabled people into membership organizations that could educate themselves and the community and work towards change. These organizations were small compared to the long history of the organized blind and the shorter history of the deaf. The mentally retarded while having a long history, were organized only through parent groups. The mentally ill were not well organized. There was a desire in the beginning, of organizing the physically disabled, to reach out and attempt a coalition with other disabled organizations; at the local levels, at the state levels, and if possible at the national level. This attempt over the years was successful at all levels in various degrees. The best example being the American Coalition of Citizens with Disabilities that grew in the mid-seventies to embrace most of the disabled groups and organizations working on a state level.

Some of these organizations wanted to educate the various identifiable leaders of the disabled within the groups, in the political machinery for passing legislation and in how to use power and influence to accomplish change in the community. Other organizations wanted to know how to find money to support the efforts of the organization. This came about through individual donations, fund raising techniques, foundations, corporations, unions, and wherever money could be found. Certain key people became very good at making connections, making the political friends in order to promote the desired piece of legislation and follow-through the lobbying process. Other key people became good at finding and raising money for an organization and its direct services. Making these political connections and money connections became something of a closely guarded secret in that money and political connections were not always freely shared with others and became essentially special knowledge for the privileged few.

One of the skills that was quickly learned by the leadership that developed in the disabled organizations was the ability to manipulate guilt - a talent and a technique that was used in other social movement organizations. Essentially this was the knowledge that those who had money, power and privilege, also had guilt because they had the better things in life often denied to disabled people. As such, the manipulation of the guilt of those persons who discriminated against the disabled, who held stereotypes, etc., became a very rewarding technique, both politically and personally. Also the use of logical arguments, well-reasoned arguments and statistics showing cost effectiveness; sound, logical, rational justification for the integration of the disabled and the development of necessary support programs and policies, was another very special talent that was developed.

The use of the media was absolutely essential in communicating a feeling to the politicians and people who had money that the disabled were a knowledgeable group, indeed it was important that certain key leaders be seen as having the support of all disabled people and a knowledge of the issues and as such could be seen as representatives of disabled people. Media recognition was immediately useful for manipulating guilt and for leveraging the political process. Demonstrations as media events were very useful in combining all three techniques. For the media, the basic de-

mand of the movement was equal rights, based on the same themes as other social movements' equal rights and full participation in the community. This could take the form along a whole spectrum of society's problems and on any issue. Legislation became a favored measure of success for guaranteeing equal rights and full participation. There was a strong feeling that if the Civil Rights Act had an additional clause of protecting the handicapped in terms of forbidding discrimination, we would have reached a milestone. The possiblity of enacting into law Section 504 which dealt with discrimination in regards to only those programs that received federal money was hotly contested by the disabled. The disabled eventually won through a great deal of demonstration and lobbying activity. Public Law 94-142, the education for all Handicapped Children's Act, for example, was a very important law. There were many other developments, those two in '73 and '75 and later in the '78 Rehab Act Amendments that expanded upon those protections passed in '73. It all helped to develop a fair amount of law supporting equal rights for disabled people. If not the full civil rights, they did lead towards improved participation of disabled people in society.

Yet, there were many problems in these developments. Once the laws were passed, the enforcement of them and the money to implement them was usually not existent. This was but another indication of the emptiness of the political promises that were made. These pieces of legislation in many ways were ahead of the ability of the disabled organizations to monitor their enforcement, or the communities' readiness to deal with the idea of full participation of the disabled throughout all community activity, or the elimination of previous discriminatory practices and attitudes. Due to these two problems these laws were rarely enforced and in many ways give a platform for opponents of further legal rights or economic support to contest their validity. Often people would point to these laws and say we've done enough and we don't need to do more now, there are other pressing needs.

One of the key areas we wanted to initiate was new and progressive services to the disabled whereby the disabled would have the necessary support services and access to existing community services, to live independently in the community with full and equal access to all segments of community life. In trying to implement these progressive service models, some small segments of the total disabled population proposed that disabled people themselves should have controlling influence over the delivery of these services. In fact we did develop service models which were under control of the disabled and they were very successful. Larger portions of the disabled people only went so far as to demand the participation of disabled people in decision making at all levels; feeling that control by disabled people was either unnecessary to ask for or was not within traditional democratic values. The concept of the participation of disabled people in decision-making continued to meet with a great deal of resistance at all levels of government and social services administrations. To this day this concept is partially acknowledged and encouraged in some states. In some programs a very good participation by the disabled is occuring. The vast majority of programs either give token service or have no participation by the disabled at all. Too often only lip service has been given to the concept of the disabled involved in decision-making regarding their destiny.

One of the key problems in the organizing of disabled people, in the development of coalitions, in the pursuing of political objectives, new laws, new policies and new services is that of disagreement between disabled individuals, disabled groups and even various disability groups themselves. This disagreement in tactics or philosophy would lead to one group vying to outmaneuver or undermine the opposing philosophies or proposed programs of another group. This was often the case with more conservative disabled people who felt that the demands being made by the more militant disabled people were made too quickly or in the wrong manner. The conservative disabled were often looked at as joining with the establishment and with the "enemy", and as such they were excluded from participation and decision making. This often led to elitism and cliques developing within the leadership of the disabled movement. Sometimes only a clique would be in power and making decisions as opposed to a united front, with all people being involved. The less elite disabled people were not always allowed to participate in delicate negotiations due to the feeling that they lacked experience in the development of the movement. Again this led to a division between potential allies and the disillusionment or loss of many supporters who could have created a larger, broader-based coalition for change.

Where Are We Now?

In the late 1970's and 1980, our efforts for integration have now had time to show the successes or failures that have resulted from our policies and programs. In the area of schools, more disabled people are being integrated into the colleges and are having accss to the same kind of education open to everyone else. High school and elementary education has more participation by severely disabled people as opposed to the previous segregation into special education schools. Still, large numbers of disabled do not get appropriate individual education plans, which are required to be developed for them with their input. Parents are usually not educated about the rights of their disabled children. Too many schools are still resisting the full integration of disabled students, but it has definitely improved from the situation of over a decade ago.

Employment has often been a major goal for proponents of the integration of disabled people into the community, to show that their ability to produce is equal to people who are nondisabled. There have been more efforts for employment than for any other problem of disability. Efforts at integration have still led to only a few elite people getting employment. There are scattered cases of companies or small businesses hiring disabled people and boasting of its success. But by and large the laws against discrimination have not seriously increased the employment rate of disabled

people. The disincentives for working that go along with many of the support benefits have encouraged disabled people from actually being able to work. The lack of free medical treatment or at least affordable medical treatment for those who are severely disabled has gone a long way toward keeping disabled people out of the job market. Stereotyped attitudes and the competition for jobs, since many people need jobs and jobs are becoming hard to get, has led to the disabled being among the last hired.

In those communities where there have been active disabled organizations promoting the rights and educating people about full participation of disabled people in the community, life is better for some disabled people. There are a few examples of communities that are better, but this is primarily in larger towns and cities. And only a small part of those urban community services or activities has shown any improvement.

In the past ten years, millions of dollars have been given to provide housing for the disabled and the elderly, since they were lumped together into one population to be served. At first, federal policy was to build segregated, large, apartment complexes for the disabled. Now the policy is to build small, segregated, complexes for the disabled and to subsidize rents in other houses. This is still not enough to meet the need. Remodeling housing and adaptive housing have not seriously been tried at all. New housing is still being built in massive numbers across the country with no regard at all to insuring adequate accessibility. Some attempts have been made in a few states to put this into the building codes, but where it is the law, the implementation has become a major battle-ground for the right of disabled people to equal participation in the community, with the implementation battle being based on money or the lack of it. The reactionaries or those people who feel that costs should be considered before the equal rights and civil rights of other people, are using transportation as a current issue to stop any further rights and benefits to the disabled. They argue that it is cheaper to have transportation door-to-door rather than make long-term commitments of accessible mass transportation, i.e. heavy rail, subway, light rail. A great deal of effort by organizations of disabled persons has gone into the area of mass transportation since it is considered a major component of disabled mobility and integration throughout the community.

After ten years, have equal rights been obtained? My answer would be not yet! Equal rights are still an ideal and a goal and by no means have they been obtained. Some mechanisms for equal rights do exist under the law, but in terms of the community, in terms of day to day living, equal rights are still an abstract concept and an ideal still to be achieved. This is not to say that there are not some disabled people who are living better through the efforts of the last decade. There are many disabled people who have gotten a better education, more work, and a better place to live. But when these people are compared to the total population of disabled people, it is negligible. The results of the last ten years has developed a new elite class of disabled people, those who know how to work the system and benefit from existing opportunities. The vast number of disabled people have really not had their living conditions and opportunities changed. This can best be illustrated through the existence of a majority of disabled people still living below the poverty level, and usually on a bare subsistence income. The basic subsistence allowance that was given to disabled people in the '70's has not even kept pace with inflation. This lack of a cost of living increase must be seen as a direct action by the government - state and federal - to reduce the amount of economic subsidization to disabled people. People are now living on much less than they were a decade ago. The forced dependency and the human misery that this is causing, in many ways offsets a great deal of the gains and, in my mind, this more than anything else illustrates the illusionary nature and the elite status of integration that has been won for some disabled people.

The organizing of the disabled has increased over the decade and the organizations have increased in numbers, but they've reached a plateau and are not sizeably increasing on a yearly basis. Their leadership is often the same people with the positions being rotated among the same old people year after year. The coalitions are not really any stronger. The distrust and the cliques are still operating. Many of the good people have left these organizations disillusioned and burned out. Very few, if any, people are coming in and even they fall prey to the same errors that have historically characterized these organizations because they have not yet been able to change the direction and nature of the organized activities. They often have no vision of where to go next and in what direction to make meaningful changes. They do not have "good politics".

In the area of direct services, the attempt to provide new and progressive services to the disabled is best characterized through what is called "the independent living movement". Roughly, in the early 1970's there was an attempt to provide direct services to disabled people that were essentially run and decided by disabled people. These independent living centers provided not only direct services, but advocacy in the community and relied upon a great deal of volunteer effort. Over the years they gradually grew larger in order to meet the gaps in services for disabled people in the community. In growing larger they started changing the nature of what they were - how they provided the services and who they hired. They found money outside the community in order to support their continuing existence, and developed projects that were not always directly related to the community. Even though these independent living centers were phenomenal in providing more independent services to disabled people, it was very difficult to find or receive money to either maintain existing services or to start new ones. Increasingly, efforts were turned towards government agencies and the government itself to provide money to support the development of new centers. The idea being that the end justifies the means, and the possiblity of co-optation. What is happening to the centers today is similar to the problems with legislation for equal rights, in that laws were passed and implementation attempted

before the community was ready. The independent living centers are rapidly finding that as they are trying to be developed in new places, there are not enough disabled people with political experience in community services in order to develop the centers or maintain strong influence and control by disabled people.

Often the inexperience of disabled people in running large-scale organizations has led to competing factions in the centers and internal troubles. This is not unlike any other new enterprise, but certainly the lack of proper preparation of a community for the equal participation of disabled people has led to many problems in the development of new centers. In addition, the extensive use of government money has taken the control away from the community and from the disabled and given it to people who are not disabled and not at the community level to decide where the center should be and how it should be operated. This has led to a decrease in the involvment of disabled people in decision-making over an independent living center's services and an increasing trend toward professionalism and non-disabled control in the development of these services.

The development of professionalism in the delivery of services in an independent living center is characterized by hiring people who have qualifications and prior experience in social service delivery fields as opposed to hiring disabled people with life experience and sensitivity in relating to the needs of other disabled people. The professional orientation leads to more non-disabled people being hired based on qualifications rather than a disabled person being hired based on qualifications rather than a disabled person being hired based on the value of peer relationships. The professionalization is also characterized by increased bureaucratic rules and procedures for giving services, and also by a narrow, specialized ability to serve. Another manifestation is the limiting of services to specific categories and groups. In those organizations controlled by the disabled and who have hired the disabled to provide services, professionalization of those services is increasing due to a desire to specialize. For example - a particular service such as financial benefits counseling - the staff person will become very familiar with rules, regulations and procedures of the various governmental agencies and become the conduit for the disabled client to undrstand and work within the system. The problems of the disabled client that exist **because** of the system and its rules and procedures cannot be dealt with because the service provider knows the rules and how to use them, but is not able to deal with a problem that is basically caused by the rules and regulations that exist in the agency. The disabled specialist in some of the independent living centers are becoming an interface for the existing service system. As such, they become part of that system.

The access of disabled people to community services has improved in various urban cities through the efforts of advocacy groups and independent living programs, where they exist. Community service agencies are more aware in those areas. There are restaurants, city halls, theaters, etc., becoming accessible for the physically disabled. Attempts to open up the city recreation or leisure programs are being somewhat successful. But in those cities where advocacy does not exist and there are no independent living programs, the cities are pretty much going along as they always have, with very minor if any, changes to accommodate the needs of the disabled. The same laws that are being used successfully in some major cities are still unenforced in others. These laws are not enforced where disabled people are not actively trying to enforce them.

Even with the attempts of independent living programs and other advocacy organizations to provide better services and a more equal opportunity to participate in the community, all disability groups have not been reached equally. The physically disabled have been primarily the main recipients of the activities of many vocal disabled organizations in the last decade, the deaf and blind have trailed in the receiving of benefits. The advocates for the mentally retarded have pursued their own directions in many ways, though at certain significant times all disabled groups have come together to take a stand and successfully fight off attempts to rescind existing protection and hard-won rights. Often this uniting for a common cause is diffused, weak and more of a "knee-jerk" reaction to a severe attack on existing services or legal rights.

Only in the urban areas can we point to any changes of significance over the last decade. The rural areas of our country are still without any noticeable change in attitude, programs, access or barrier removal for any disability group. The ethnic minorities of this country have been, by and large, ignored and secondary recipients of any benefit of or activities of the disabled movement in the last decade. This is due to the essentially white, middle class nature of the disabled movement in this country which has goals and values that are first in their own interests and secondarily, in a filtering down process, for the ethnic minority and poor white population.

The summation of where we are now after ten years of attempting to integrate the disabled in this country is that there has not been any significant change in the basic community attitude or perception of disabled people. There has been no major change in the delivery of services to disabled people by existing community service agencies. There has been little or no enforcement of any of the legal rights that have been won by disabled people in the last decade.

It would be unfair to state that there has been nothing worthwhile at a societal level from this decade of disabled activity. Yet the gains that can be pointed to are few and are primarily for a handful of disabled people as compared to the vast numbers that exist in our country. It would **not** be unfair to make comparisons between the black and disabled movements, in that the conditions of most black people in this country have not greatly changed and in many cases have worsened in the past 10 to 15 years. There have been attitudinal changes and involvement of black people in sections of society life where before they had not been. Like the blacks, the disabled have made strides in being seen in the community where before, they were not; in becoming employed in industry where before they were not; going to

school where before they were not; and living in community neighborhoods where before they could not; going to restaurants where before they could not; and winning political rights where before they did not exist.

Changes have been made and can be seen as for the benefit of disabled people in general. But I believe that it is hard to announce these gains as overwhelming victories when so many disabled people in this country still live at or below a poverty existence. So many disabled people are still without basic supportive devices, many elderly physically disabled are still confined to institutions, many mentally disabled are left to wander the streets and sleep under bridges. The mentallly retarded are still sheltered and protected and not given the escape of drugs because of the attitude of the community. This and more makes it difficult to say this past decade has been overwhelming in its changes for the better.

What Lessons Are To Be Learned From Our Experiences Here In The Last 10 Years

Is integration the correct way to obtain the equal participation of disabled people in the community? The basic feeling behind this is one of forcing change since the historical development of the community isolated or segregated the disabled. There seems to be a feeling in the concept of integration of demanding from the community what they are not ready to give.

It seems that when we try to make demands on the community that at best a surface level of compliance with integration can be expected. Though an adequate number of years has not passed either for the disabled movement or the black movement, in those communities where attempts at integration through legal mandate have been enforced, it has been proven that some gains can be achieved.

Would it not be more preferable to develop the community's awareness of the value of all human beings, or the richness of sensitivity to all human beings, of the basic fragility of the human body in day-to-day living, so that disability is not looked at as something outside of normal human experience, to be kept out, isolated, feared, but instead as a part of living, a normal progression of human existence.

It must be remembered that the community and its values and policies are shaped and moved by the social and economic forces of the environment. Therefore, if the social and economic forces can be manipulated or directed to the point that integration becomes the norm, then what we will find is disabled people participating fully because integration already is a part of the community's values and structure.

Attitudes

It seems that changing the community's attitudes toward the disabled is of prime importance if there is to be any effective change. Attitudes are not something that exist alone, they come from people's feelings, from people's daily lives and experiences; from feelings of insecurity and fears that are generated by competition, by a desire for individual salvation; by lack of employment; by fears of being abandonded because the family structure no longer is concerned about the elderly or the disabled. It is possible to get people to look at their stereotypes, prejudices and fears, to recognize where those fears and prejudices come from and attempt to reject them. Therefore it is ncessary to educate people about where their attitudes come from - from daily life experiences, from parents and customs. It is necessary to educate the disabled also about the prejudices and stereotypes of non-disabled people so that disabled people won't feel that the discomfort and uneasiness they feel is coming from themselves, but will see it as the inequality and basic discriminations of those in their immediate environment. Disabled people also have prejudices and stereotypes about other disabled people and these attitudes must also be rejected.

Non-disabled people need to appreciate disabled people for their strengths, for the wisdom they have learned from their experiences, without stereotyping that wisdom and strength.

The attitudes of professional service providers have a lot in common with the basic attitudes of the communty. These professionals are often more difficult to change in their attitudes and perceptions of disabled people than others in the community. This difficulty comes about through egotism on the part of the professional who feels s/he has learned the correct approaches and correct solutions and therefore feel they have an understanding of the problems of the disabled and know what to do about them. They also have the fear that the ability to solve the problems of the disabled could be handled by non-professionally trained individuals. Thus, the professionals would not be able to support their right to a highly paid position. We have found that service providers are quick to point out the lack of training, lack of expertise or qualifications, the lack of rigorous, logical delivery of services done by non-professionals. These attitudes have undermined the attempt of disabled people and non-professionally trained community people to try and serve their own needs. This opposition is causing more problems as opposed to unifying and finding common solutions to complex problems.

Problems

We are led to the fact that often the problems of disabled people are mystified by professionals who intellectualize, analyze or compartmentalize the various aspects and problems of disabled people. This mystification means that only the correct language developed by professionals can define the problems of disabled people, only the methods used by professionasl analysts can be used to determine where the problems come from; only the models developed by professionals can provide a solution and only professionals are qualified and capable of implementing solutions. This is why the involvement in direct services of disabled people, based upon their experiences as disabled people who have learned

positive self-value and how to be independent and a participant in the community, undermines the status of professionals and their hold over services to disabled people.

Not all professionals engage in the mystification of disability and it's problems. Not all professionals look upon disabled people with hositility and fear. Many non-disabled professionals have become friends, and seek a unity in the developing of new ways and techniques to help the disabled lead better lives. The fact that there are professionals who do not support the paternalism of many service agencies, leads to a feeling of hope.

In this country (USA) competition and individualism are two of the most important forces motivating people. Competition - to get more materially, to succeed at expense of someone else, to strive to become the best and to win. These attitudes are looked upon favorably in this country. Individualism - meaning to succeed by yourself, to gain materially by yourself and for yourself. To be separate from other individuals for to share with them would lessen your competitive ability. To seek salvation by yourself because to seek salvation with others is not a victory.

These two forces keep **all** people in the society isolated from each other and especially keep disabled people from other disabled people and also from non-disabled people in the community. Competition and individualism supports and promotes the worst aspects of professionalism in service providers. Problem solving for the disabled can best be accomplished through cooperative efforts - disabled and non-disabled together, with a feeling of responsibility by an individual to better the lives of others in the community. A better life for all people, including the disabled should be the concern and responsibility of every member of the community, and not just the service providers. This kind of cooperative and responsible commitment by people of the community can only lead to a better life for disabled and non-disabled people in the community. It must be remembered that all people are becoming disabled in their lives, naturally. Support and care and sensitivity to each other in the community can only lead to a fuller and better life for all members of the community.

How Might We Begin Making Life Better For Disabled People In The Community

I think it might be good to start with a premise: "what kind of community should people live in?" This brings back two statements that have already been made about attitudes, cooperation, respect and sensitivity of people. It certainly seems true that competition and individualism do nothing to promote these qualities in people and in a community and so must be taken into consideration when efforts are made to develop a better life for disabled people. In a community, what is the prevailing value that is shared in developing life in that community? Is it one of cooperation and sensitivity or is it one of competition at the expense of other people?

In the provision of services and in working with people, it is necessary, for want of a better expression, to "get in touch" with humanness. It isn't good enough to provide services because of a moral commitment or an ideal of what you hope to accomplish in the community. Services are best provided through a recognition of the value of another human being, no matter how different, no matter how poor or lacking in education. These are not values that determine the worth of an individual to receive services. This is also why we sometimes encourage the use of disabled people to provide services to other disabled people because the suffering that a disabled person has gone through, the discrimination and oppression, can make it possible for them to get in touch with their own humanity and the humanity of other people. They can relate to other disabled people through a sense of shared humanity. It is also important to note that it is not the quantity of services provided or the number of disabled people made productive or independent that is important, but the quality of the relationship between the provider and the receiver of services.

Productivity, numbers, statistics often get in the way of sensitivity and respect of another human being and lead to the qualitative failure of many programs. It is important in beginning a program to start small with personal commitment, personal involvement, sensitivity and the ability to relate in a human way. If at first the change agency or leader is a person from outside the community, it is important to immediately find people from the community who are leaders and who can conceptualize what it is that you want to share with them that would better their lives and the lives of others in the community. It is important in teaching to, and learning from these new leaders and providers of services to the community, not only the theory of what is possible in that community and methods, but also to practice them in day-to-day experience. When the people will not accept what you teach and practice and if they find it foreign to their lives, then it must be modified. That is the practical day-to-day, person-to-person, experience that will tell you if what you do is correct. It is necessary to be open to the community's criticism, complaints, or desires. The correctness and purity of theory is never an excuse to oppress a community with a program and services they do not want.

One of the most difficult things to guarantee in the development of new programs and services is that people will be able to maintain their personal independent freedom to make choices for themselves. It is this area that the problem of "the end justifies the means" occurs and interferes with true community involvement. When we believe the model is correct and is beneficial to most people, we often try to educate the people as to why these models are good for them, why they should operate services in such a manner and why the best thing they could do is to develop these new program. Often we forget that what is correct for the teachers came about through the struggle of trying to find the correct way to provide services, what mistakes did we make, and how we best analyze them. It was this process which brought about our understanding. Maybe it is not always in the best interest to give them the end product of other people's struggles and mistakes. Maybe we need to consider that it is better for people if we help them to learn their own

solutions, to make their own mistakes, to be there only as a resource and to give encouragement when necessary, as opposed to having the answer and being the teacher to the solution for their community. We should recognize that change will always happen in a community, and even if it is not always for the betterment of all people, it will happen. Maybe recognition of this will eventually lead to the non-oppressive development of services in the community and not the models of a few people have succeeded in developing, and in imposing upon others who've learned that particular answer through their own struggles and life experiences.

I would like to close this part of the paper with an excerpt from a paper by David Werner, titled "Health Care and Human Dignity" (1976). He makes eleven points on developing services in a rural area that I have modified to be relevant for services to disabled persons, but I think they're still appropriate to anyone attempting the development of a better life for disabled people.

1. Decentralization. This means relative autonomy at every level. Advice and coordination from the top. Planning and self-direction from the bottom.

2. Greater self-sufficiency at the community level. This is, of course, implicit in decentralization. The more a community itself can carry the weight of its own service activities, both in cost and personnel, the less paralyzed it will be by breakdowns in communication or financial support from a parent agency.

3. Open-ended planning. For all the talk about disabled input in policy making, too often a program's objectives and plans have been meticulously formulated long before the recipient communities have been consulted. If the people's felt needs are truly to be taken into account, program plans must be open-ended and flexible. It is essential that direct service workers and representatives from the community - not just top officials - attend and actively participate in policy planning and policy changing sessions.

4. Allowance for variation and growth. If a program is to evolve, alternatives must be tried and compared. Substantial arrangements for conceiving and testing new approaches, methods and points of view should be built into the ongoing program. Also private or nongovernment projects should be observed and learned from, not forced to conform or stamped out.

5. Planned obsolescence of outside input. If a self-sufficiency at the community level is indeed to be considered a goal, it is advisable that a cut-off date for external help be set from the first. All input of funds, materials and personnel should be conscientiously directed toward reaching the earliest possible date when such assistance is no longer needed. Thus the outsider's or agent-of-change's first job, should be to teach local persons to take his place and, in so doing, make himself dispensable. Outside funding, likewise, should not underwrite ongoing activity, but should be in the form of 'seed' money or loans to help launch undertakings which will subsequently carry their own ongoing costs. It should be noted that the need for initial seed money sufficient to illustrate the potential of the activity is necessary in programs for the disabled. That often a community that has never experienced services for the disabled will be less likely to initiate such activities since they have no concept of what you're talking about until they see it in action and how it will affect their lives.

6. Deprofessionalization and deinstitutionalization. We have to get away from the idea that services to the disabled and integration into the community is something to be delivered or to be arrived at. Primarily, it should not be delivered, but encouraged. Obviously, there are some aspects of disability such as the medical support system, which will always require professional help - but these could be far fewer than is usually supposed. Most of the service needs of disabled people could be handled better by informed people in their own homes and in a supportive community working together. Disabled services will only become truly equitable to the extent that there is less dependency on professional or institutionalized help and more mutual self-care. This means more training, involvement and responsibility for and by the people themselves. It should include continuing education opportunities for the people of the community which reinforce their staying in and serving their communities.

7. More basic information about disabilities and how to be independent. For a long time, only medical doctors and the service professionals around disability had the information about the complexities of disability health care - what to expect when you got sick, what to do about it, where to get direct services in the community, etc. This holding on of information by these professionals has kept disabled people from being able to do very rudimentary self-care and cooperative service providing. It is necessary to open up this information to all people in the community and actively teach people about their own bodies, illnesses, and disability, so they are better informed on how to take care of themselves. This is better than waiting until they're sick to see a doctor, then not knowing what was done to them afterwards, or having to go through an information broker in order to receive support services in the community.

8. More feedback between service professionals and community services providers. When disabled services providers refer an individual to a services professional, that professional should always feedback to the community service worker, explaining in full clear detail and simple language about the case. This can and should be an important part of the service provider's and the professional's continuing education.

Earlier orientation of service professionals. From the very beginning of their training, service professionals

should be involved in their community, its problems, its experiences and its joys, and be encouraged to learn from experienced disabled people and service providers, who are disabled themselves, in the community.

10. Greater appreciation and respect for disabled people, their skills, their intelligence, their potential and their unique experiences and attitudes as a result of being disabled. Disabled people and especially disabled service providers are often treated like children or amateurs by their more highly educated trainers and supervisors. This is a great mistake. People with little formal education often have their own special insight, skills and powers of observation which intellectuals have never acquired and therefore fail to perceive. If this innate knowledge and skill is appreciated, and integrated into the disabled service process, this will not only make it more truly community oriented and viable, but will help preserve the individual strengths and dignity of the service provider and disabled people. I cannot emphasize enough how important it is that professional service planners, instructors, supervisors and trainers be "tuned in" to the capabilities and special strengths of the people they work with.

11. That the directors and the key personnel who are service providers in a program be people who are human. (I have not modified or changed this story by David Werner because I felt the essence of the example is easily understood. The principle here transcends the subject.) "This is the last, most subjective and perhaps most important point I want to make. Let me illustrate it with an example:

In Costa Rica there is a regional program of rural health care under the auspices of the Health Ministry which differs in important ways from the rural health system in the country as a whole. It has enthusiastic community participation and a remarkable impact on overall health. It may well have the lowest incidence of child and maternal mortality in rural Latin America. Its director is a pediatrician and a poet, as well as one of the warmest and hardest-working people I have met. The day I accompanied him on his trip to a half-dozen village health posts we didn't even stop for lunch, because he was so eager to get to the last post before night fell. He assumed I was just as eager. And I was; his enthusiasm was that contagious!

I will never forget our arrival at one of the posts. It was the day of an 'under-fives' clinic. Mothers and patients were gathered on the porch of the modest building. As we approached, the doctor began to introduce me, explaining that I worked with rural health in Mexico and was the author of ***Donde No Hay Doctor.** Frantically, I looked this way and that for the health worker or nurse to whom I was introduced. As persons began to move forward to greet me, I suddenly realized he was introducing me to **all the people,** as he would to his own family. Obviously he cared for the villagers, respected them, and felt on the same level with them.

This, I must confess, was a new experience for me. I was used to being marched past the waiting lines of patients and being introduced to the health worker, who was instructed to show me around and answer my questions, while the patient, whose consultation we had interrupted, silently waited.

"This man is an exception!" I thought to myself. In our visits throughout Latin America, we found almost invariably that the truly outstanding programs have at least one or two key people who are exceptional human beings. These people attract others like themselves. And the genuine concern of people for people, of joy in doing a job well, of a sense of service, and the sharing of knowledge permeates the entire program clear down to the village worker and members of the community itself.

People are what make health care work.

Translated from the Spanish, ***Where There Is No Physician,*** *David Werner, 1976.*

Excerpts of Reviews and Comments

The following are excerpts of reviews, comments and questions raised by the Switzer Fellows. These are presented to further stimulate thinking as well as action as it relates to the content of the fourth chapter by Bruce M. Curtis.

"There are advantages as well as disadvantages in tracing the actions of disabled people to achieve greater integration within society from the perspective of one group and one strata (white, middle-class) within one society (contemporary U.S.A.) as Mr. Curtis has done. The advantage lies in the genuineness and reality of the experience reported; the disadvantage relates to assessing whether or not the experience represents a sufficient basis for understanding or generalization.

Mr. Curtis recognizes that it was only as new medical techniques and improved support services reached large numbers of disabled people that it became possible for people who found themselves to be medically stable to assess what to do with their lives. Does this mean that basic services are a necessary prerequisite to the participation of disabled people in societal life? If so, most of the disabled people in the world will not achieve that goal in their lifetimes. He draws attention to the ignorance about disability among large groups of key people--social workers, employers, community planners, administrators. He notes the isolation and poverty fostered by current practices and conditions upon the lives of disabled people and he considers that only a small elite have succeeded in breaking free of these debilitating realities. Is this not an injunction to society to regard the problems of disabled people as societal rather than individual? At the same time, does not this position mean that the solution requires active participation of everyone in society to become concerned, to become better informed and to take positive action?

Another intriguing issue raised by this analysis is whether involvement of the family is covertly a means to keep disabled people forever dependent and to limit the extent of governmental and social obligation, particularly financially, as a result. Strengthening of family and community capabilities to deal more effectively with disability has been at the core of recent international action strategies. I would find a further discussion of this point to be illuminating."
--Susan Hammerman

"The excellent paper by Bruce Curtis carries extra weight because of his own experience as a disabled person deeply involved in leadership roles in organizations of and for the disabled. While he has written only about situations in the United States, the majority of his points would be true in varying degrees in most countries. For example, the problems of:

*attitudes toward the disabled which force dependency,
*acceptance in social, educational and employment situations, isolation,
*architectural barriers,
*untrained, unknowledgeable persons working with the disabled,
*the inexperience of the disabled in running organizations and/or programs,
*disagreements among disabled individuals, among groups of disabled, and among groups representing persons with various disabilities,
*jobs,
*forced integration placing demands which communities are not ready to accept,
*greater progress in service to the disabled in urban than in rural areas.

However, Mr. Curtis' 40 or more points do not apply equally well in all developed nations. The balance is tipped in a number of ways as the richer countries have worked out solutions or have found ways of avoiding the problems. What is or is not done for the handicapped is strongly related in these countries to what is offered and demanded of all the citizens.

Most international studies consider only the condition of the handicapped person without looking at the community in which he lives. There is not automatic relevance of solutions from one country to another.

In developing nations the problems are multiplied to infinity. Huge percentages of populations have health problems, minimal or no education, minimal or no governmental assistance for clean water, housing, sewage or roads. The lives of the disabled are tragic and beyond belief, but the lives of the non-handicapped may be little better."
--Jeanne R. Kenmore, Ph.D.

"The reader of this 'action paper' is left with a strong sense and feeling of the separation, hopelessness and isolation that has been and is experienced by persons with disabilities. In the paper, the author focuses primarily on physical disabilities and has not broadened the paper to include those with mental, emotional and developmental disabilities.

In the context of 'full integration of disabled persons', it would be valuable, however, to include more specific examples throughout the paper of solutions to the problems highlighted. The author gives a general picture of critical concerns and issues over the past 10 years, including equal rights, housing, transportation, education, attitudes, direct services and independent living. One is left, however with the desire to have details that make a stronger case for the situation presented. For example, what is meant by 'integration (has) still led to only a few elite people getting employment?' What has been accomplished, who are the elite, and what suggestions are there for ways others can get employment? What is the responsibility of this 'new elite class of disabled people?'

Overall, the paper is perceptive and insightful and addresses some of the most basic and practical issues facing the disabled population."

--Mercedese M. Miller

"If the ultimate goal of our efforts is the integration of disabled persons as full and equal participants in the life of the community, and the integration of disability prevention efforts in community health education and health care programs, non-rehabilitation government and private agencies indeed, all organizations in the community must play a role. In a social and a practical sense, it is not the individual disabled person who needs rehabilitating, but rather it is society that needs rehabilitating. If the vast numbers of children, youth and adults, men and women with physical and mental impairments in the developing countries of the world are to even survive, let alone be reached by standard community services, more actors than rehabilitation professionals must become involved."

--Robert B. Ransom

"The paper is concerned with the dynamics of power within primary consumer movements. The author's description of the experience that groups of physically disabled people have encountered suggests that membership of primary consumer groups experience organizational behaviors not unlike any other voluntary organization. Leadership, elitism and other problems common to human organizations emerge as the movement becomes established. Being at the 'bottom of the ladder' and face with a common 'enemy' does not, per se, act as a deterrent to typical interrelationship problems.

Elitism **between** disability groups is even more prevalent. Being identified with other groups who are perceived as deviant by society creates resentment. One principle of the normalization ideology is to avoid grouping of people with different disabilities (known as deviancy juxtaposition). The more constructive approach is to stream each person into normal settings.

The author's claim that 'there has not been any signficant change in the basic community attitude or perception of disabled people...' and '...little or no enforcement of any...legal rights...', could be questioned. It may not appear that there has been progress because of the newer expectations of disabled people.

Expectations among disability movements tend to rise faster than changes that occur. Frequently, different baselines are used to measure progress. This can result in proving positive or negative results around the same issue."

--G. Allan Roeher, Ph.D.

"Equality is an abstraction, not only in the developed nations but also in the developing. Mr. Curtis discusses the efforts of disabled people in the United States and the weaknesses of the present systems of service delivery and social integration. His findings, however, are pertinent to developing nations albeit they are overly idealistic and anit-professional.

Is equality a myth? Can attitudes be changed, and how? If policy and direction is to come from the people concerned (i.e. the disabled population), what government will fund this freedom of movement and activity? Should government funds be diverted to disabled people on a programmed basis or should disabled people themselves seek their own funding as needed? Is there an overemphasis on professionalism and the 'mystique' of disability generated by professionalism?

Can varying disability groups find a common goal to encourage unity and unified actions within a society? Do common goals further the cause of disability or do they damage it? (An example which Mr. Curtis touches on is the issue of accessible transportation in the U.S., an issue which is of utmost concern to mobility-limited disabled people but of little concern to those with hidden and non-mobility disabilities.)"

--Robert H. Ruffner

"An area in regard to Mr. Curtis' paper that I would like to comment on is that having to do with the relationship of non-disabled professionals, disabled professionals and consumers. It is clear that a partnership is called for. Disabled persons must tune into the value of professionals as well as having a healthy criticism toward their "professionalism". In other words, just as disabled persons are looking for professionals to tune in to the true needs of the disabled, the disabled must 'educate' non-disabled professionals in a climate of trust. The adversary position is clearly counter-productive.

Mr. Curtis neglected to comment on how the Rehabilitation Act of '73 affected the lives of disabled people. In fact, he said almost nothing about the State-Federal program in Vocational Rehabilitation; which, as flawed as it is, has been instrumental in the training and employment of hundreds of thousands of disabled persons. Without this program, we would be back in the Stone Age with regard to independence of disabled persons."
--Diane Woods

Summary of Recommendations

The following is a brief summary of the recommendations and implications for action as developed by the Switzer Fellows as it relates to the topic of the fourth chapter. (The recorder was Ms. Diane Woods)

General Statement

Disabled people throughout the world should be allowed the opportunity to choose a lifestyle that is compatible with personal preference within the particular societal frame of reference. A system of rehabilitation services (and a governmental recognition of the need to provide special services to disabled people) is a prerequisite for the development of consumer involvement.

Active involvement of disabled people in decisions about themselves is the necessary ingredient for integration. Although a system of services and adequate delivery of these services is needed in order to promote 'consumer involvement', there is a warning: too many 'benefits' can sometimes be as limiting as too few benefits **with respect to consumer activism and involvement.**

The family is usually the key to the way a disabled person does or does not integrate into society. Services and programs for the disabled should take into consideration the family's cultural and social beliefs, attitudes and practices. This may dictate the way a person becomes "independent" or chooses "not to fit" into a societal and familial context. However, a disabled person's **options should be maximized** through the realistic systems of service delivery in rehabilitation.

Recommendations for Training

1. **Disabled activist and new rehabilitation professionals should seek and be able to obtain education and information from an "historical perspective" in rehabilitation and disability. Much has happened in the way of services that may be unknown to the new professional as well as the newly disabled person.**
2. **Disabled people throughout the world need role models. Training in taking charge of one's own life should be promoted by making disabled people in action more visible -- on jobs, in sports, in schools, and in various community activities. This can be done by active disabled people and through media cooperation.**
3. **The general public must receive information regarding the capabilities of disabled people through daily contact with disabled people and through the media.**
4. **There is a need for relevant translations of films and other training materials for use in developing countries (e.g. "KIDS ON THE BLOCK" is a very useful film in this regard).**
5. **Training opportunities for disabled people in professional areas related to disability and rehabilitation have to be expanded and "apprenticeships" should be considered.**
6. **The need exists in training professionals (including physicians) to give higher priority to the social implications of disability. The opportunity exists to carry this out in developing countries where the medical model may not be so firmly entrenched.**
7. **There is a need to stress the role of the disabled person (and their family) as partners in all rehabilitation efforts.**

Research

There is a need to evaluate and disseminate information regarding the impact of disabled people in the community based on different models of community involvement.

Legislation and Rehabilitation Programming

There is a need to include research and re-education in attitudes toward the disabled in the development of new programming and current legislation in rehabilitation.

Policy Development

1. **It is suggested that the recommendations set forth in the Curtis paper based on David Werner's postulations be adopted as policy statements in "helping disabled people integrated in society."**
2. **Leadership from disabled persons should be developed and expanded throughout the world.**
3. **Disabled persons should be sought out to actively participate in the design, development and operation of rehabiliation programs.**

4. **Families should be actively involved in the educational planning and medical treatment for their disabled children.**
5. **The family unit's strength should be examined and techniques developed for supporting the family in encouraging the development of independence of the disabled family member.**

SWITZER FELLOWS: Fellows here are, left to right: Dr. Michael Marge, Dr. Martin E. McCavitt, Dr. Elizabeth Pan, James S. Peters II, Robert E. Ransom, and Dr. G. Allan Roeher.

Chapter Five
By Elizabeth Pan, Ph.D. and Barbara Duncan

Disseminating Information For Rehabilitation Of Disabled Persons: An International Approach

Summary Comments

This paper is especially valuable for its intensive overview of the mechanisms which have currency in dissemination of rehabilitation information. The present situation is the product of unplanned evolution rather than systemic development and growth. In some three decades, the flow of literature has changed from a trickle to a rushing torrent, with several thousand new text books and other major items emerging annually; and an even greater flood of lesser publications (articles and papers) in non-professional publications, and available in unpublished form.

Paralleling this information "explosion" has been the growth and usage of computer technology for storage and retrieval of this large and otherwise seemingly unmanageable quantity of subject matter. The computerized data banking also evolved in a rather laissez-faire fashion, leading to the disarray and discontinuity of activity - as portrayed in the paper.

Attempts to bring order out of chaos has not, as this paper reveals, been successful. The low utilization, high unit cost, and constrained funding has confounded finding solutions.

Fortunately, new or improved solutions are emerging. One example is the use of what has been called "informatics" (new terminology and "buzz" words are constantly appearing). This combines the technology of telecommunications with computers, in order to permit "dialoguing" around problem issues between various dispersed sources of information and knowledge. These systems depend on existing information sources, and don't require central, physical consolidation of information banks and other sources of knowledge. This method could also sidestep the "territorial" problems of agency jurisdictions.

From the international perspective, it is essential to recognize that the information needs of the consumer/service provider are different in Western countries from those of developing nations (but not so different in the research and policy development areas).

Comments by G. Allan Roeher

A comprehensive review of the literature on information dissemination in rehabilitation by Senkevitch and Roth (forthcoming chapter in the Annual Review of Rehabilitation) identified about 100 relevant citations, 84 percent of which were published after 1970. Of this number, 19 can be considered descriptions of specific programs, 22 are directories or guides to sources of information, and the rest are elucidations on what the problems really are, why we have the problems, and what we should do about them. What passes as research are either planning studies for establishing specific programs or surveys of existing programs. About half of the publications cited by the review were written by 15 authors. These numbers indicate that relatively few professionals are actively engaged in information dissemination problems in rehabilitation, and most of the literature on the subject is published in the last decade.

The purpose of this paper is to describe the state-of-the-art of how information is currently disseminated to the rehabilitation community, and provide a framework for assessing where we are as a basis for developing guidelines for the 1980's. For purposes of discussion in this paper, the rehabilitation community is divided into two categories:

*** Providers of rehabilitation services including professionals, volunteers, administrators and policy makers, researchers and educators**

*** Disabled individuals who need these services, their families, and the general public**

Within each category, we will describe:

*** Who they are**

*** What their information needs are**

*** How information is now disseminated to them and the technologies that are used in the delivery mechanisms**

Finally, we will discuss the international aspects of the problem.

I. Rehabilitation Service Providers

A. Information Needs

The providers of rehabilitation services consist of two types: those who provide services to disabled individuals as professionals and those who work as volunteers.

Almost every author writing about information dissemination in rehabilitation observes the multidisciplinary nature of the field. Rehabilitation professionals include medical personnel, physical and occupational therapists, counselors, lawyers, architects, librarians, psychologists -- in short, all those people who directly provide the services needed by disabled persons and their families. Rehabilitation professionals also include those who work to support the service delivery system -- the program administrators and policy makers, the researchers and educators. In the U.S., there is a growing trend for disabled individuals to provide some of these services themselves. The growing number of disabled persons involved in the service delivery system requires that information provided to service providers must be in alternate forms. Thus, print materials should also be available in audio form, films should be captioned, meetings should provide for interpreters, etc.

Rehabilitation service providers need two kinds of work-related information: internal, or information about the organizations they work for, and external, or information about other programs, pertinent research, and innovative practices. Employers have the primary responsibility for disseminating internal information while the government and other national and international organizations supply external information in the interest of improving the overall service delivery system. The external information needs of rehabilitation service providers differ depending upon the kind of work they do. In discussing their information needs, therefore, we will speak of three subgroups of rehabilitation professionals: 1) direct service providers, 2) administrators and policy makers, and 3) researchers and educators.

We know a lot more about the information needs and preferences of counselors than we do about any other type of rehabilitation service providers. Counselors have expessed a need for: (Pan, Senkevitch and Fern, 1975)

*** Telephone referral service to direct clients to available local and national resources**

*** Technical assistance from experts**

*** A catalog of non-print resources such as films, slides, tapes**

*** Authoritative and reliable evaluation of devices and equipment**

*** Workshops on innovative approaches and procedures**

*** Multi-media "how to do it" kits**

The above list reveals a strong preference for non-print sources of information, e.g., a catalog of slides and films, and on interpreted information, e.g., evaluation of devices. While it is an exaggeration to say that counselors don't like to read, it is probably safe to say that they have very little time to go through lengthy research reports and prefer to have research findings selected, synthesized and interpreted for them, either in multi-media forms or by using expert consultants.

As we mentioned earlier, we know very little about the information needs of direct service providers other than counselors. What kinds of rehabilitation related information do doctors, as one example, need? How do they currently identify and obtain the information they need? With what results? We have not done any systematic studies that could answer these questions and yet, this is a critical aspect of information dissemination in rehabilitation. Doctors making decisions on treatment and drugs need to take into consideration the vocational and other implications of their decisions. All too often, these implications are not considered because we have not succeeded in conveying this type of information to them. Although we do not know for sure how doctors now obtain rehabilitation related information, it

would be a reasonable guess to say that they attend professional conferences, read the journals in their specialization, and consult their colleagues. It would seem logical then to use these same mechanisms to disseminate rehabilitation related information. Doctors are only one type of rehabilitation professional which we must reach by using the information dissemination mechanism of their discipline.

A small but influential subgroup within the category of rehabilitation professionals includes governmental or other decision makers within national, regional or local governmental bodies whose responsibility is to design and/or implement legislation concerning the disabled population or to plan and allocate resources, services and programs for this population. The work-related information needs of this subgroup differ somewhat from direct service providers' needs. In general, designers of legislation need basic knowledge of rights and services required to enable disabled people to make the utmost of their abilities within their chosen communities, while program and service designers and planners require more detailed and professionally evaluated information concerning the various concrete actions to be taken to implement the legislation or regulation. Where direct service providers are concerned about the "how" of service provision, administrators and policy makers primarily need infomation for decision making: options and their costs and benefits. As a group, they have expressed the need for: (Muthard and Crocker, 1974; Pan, Senkevitch and Fern, 1975; Christy, et al, 1978)

* **Statistical data obtainable by making a telphone call to a central resource**
* **Conferences on current development and new techniques**
* **Summaries of research findings**
* **Access to copies of research reports, journals, directories**
* **Lists of experts and centers of expertise**

Because administrators often need infomation for decision making, much of this information is of the internal type -- information about the organization they work in. Their external information needs are typically about other programs, innovative practices and sometimes, research findings.

Also a relatively small but influential group is the researchers and educators. Researchers and educators in rehabilitation are not essentially different from their counterparts in other disciplines: they are highly trained and typically Ph.D's; they often play the dual roles of research and education and they have relatively good access to formal information dissemination mechanisms. Rehabilitation researchers and educators have expressed a need for (Pan, Senkevitch, and Fern, 1975)

* **Listings of available publications on specific subjects with summaries**
* **State-of-the-art papers**
* **Access to copies of printed documents on request**
* **Catalog of available audiovisual materials on rehabilitation related subjects**

B. Dissemination Mechanisms

Although the information needs of rehabilitation professionals differ, they use the same formal mechanisms for retrieving information. By formal mechanisms, we mean libraries, clearinghouses, data bases, indexes, newsletters, catalogs, directories -- anything constructed willfully, as distinguished from informal mechanisms such as calling a colleague, exchanges over lunch or coffee breaks, and the like.

Formal mechanisms for disseminating information can be multi-disciplinary in scope, such as most libraries are, or they can cover a single discipline, as in **Psychological Abstracts** for psychology and **Excerpta Medica** for medicine. Until the 1950's, most formal information dissemination mechanisms were based on a single discipline. With the establishment of mission-oriented government programs, such as the National Space and Aeronautics Administration (NASA), multidisciplinary information dissemination mechanisms were created. The Defense Documentation Center (DDC), the Clearinghouse on Aging and the National Rehabilitation Information Center are all examples of formal mechanisms for disseminating information that are multidisciplinary in scope. In any one of these mechanisms, information on such diverse subjects as management, physics, electronics, metallurgy, mathematics, etc., may be found.

Formal dissemination mechanisms can also be classified by the technologies they use. There are printed mechanisms such as journals and newsletters, and tools for finding information such as indexes, catalogs, and directories. Nonprint technologies are also used: films, videotapes, slides, audio tapes, etc. As the volume of information handled increased, the need for inexpensive storage lead to the use of microforms. We can now purchase entire runs of certain newspapers and journals in microfilm and research reports on microfiche. Computers are increasingly used to store the bibliographic descriptions of printed and audiovisual documents as well as the data itself as in the census tapes. The future will see a greater merging of technologies as in the use of computers to store the contents of textbooks and even entire encyclopedias for printing as well as direct retrieval through terminals.

Time and space do not permit us to describe each and every formal dissemination mechanism in rehabilitation in the U.S. and abroad. We have instead provided a listing of examples in the appendices. A few observations of where we are in comparison to other fields might be useful.

We can list the technologies used for information dissemination in general in the following order of sophistication:

* **Print technology**
* **Non-Print or audiovisual technology**

* **Microform technology**
* **Computers used to store and retrieve bibliographic descriptions with or without abstracts**
* **Computers used to store and retrieve full texts**
* **Computers used to produce print and microform copies of full text**

The technologies used in the formal dissemination mechanisms in rehabilitation fall into all of the above categories except the last two. We are now using computers to store and retrieve full text or to produce print and microfilm copies of full text in fields other than rehabilitation.

The effectiveness of the mechanisms we develop for disseminating rehabilitation information depends not so much on the technologies we use but on the more basic tools we have for developing these mechanisms. We cannot classify documents in a collection without a classification system. Likewise, we cannot index documents without an indexing language that we can all agree with. Standard nomenclature is a major deficiency in rehabilitation and until such tools become available, dissemination mechanisms cannot function as effectively as they should.

So far, we have discussed formal dissemination mechanisms that involve the transfer of documents and other types of information products. Another type of formal dissemination mechanism involves the transfer of people. Workshops, professional conferences and meetings fall into this category. Exchange of personnel is another example. In some circumstances, this type of formal mechanism can be much more effective than those mechanisms that transfer documents. They are also usually more expensive because they serve smaller numbers of people.

Even more important than these formal mechanisms are informal networks or what information scientists call "invisible colleges." Invisible colleges have no walls, no hierarchy or organizational structure. Membership, ranging from a handful to a few hundred, centers around specific problems. Communication among members is frequently personal and informal. Invisible colleges form and dissolve as problems are solved and new ones emerge. Because they are problem oriented, invisible colleges can cross disciplinary and geographic lines.

A related mechanism for information dissemination among professionals in any field is the gatekeeper. A gatekeeper is the person in a group whom everyone consults informally for assistance in problem formulation, referral to formal and informal sources of information, and interpretation of the data. A gatekeeper is usually not in a supervisory position and is perceived as a colleague. He or she typically spends more than the usual amount of time keeping abreast of what is happening within an organization, reading the literature, attending professional conferences. Interestingly, in spite of the time spent on information gathering, gatekeepers are often one of the most productive members of the organization.

As effective as they are, informal mechanisms for disseminating information usually serve small numbers of people and are not known to others. Formal mechanisms are, therefore, necessary to supplement informal ones.

II. Disabled Persons, Their Families, and the General Public

A. Information Needs

So far, we have discussed the information needs of rehabilitation professionals, and the formal and informal mechanisms we are using to disseminate information to them. Let us now look at the information needs of disabled individuals, their families, and the general public.

Let us take the general public first. Who is the public? The public consists of everyone who has an impact on the lives of disabled people: the bus driver, the storekeeper, the employer, the postman, you and me. It is also important to remember that the public also includes disabled people.

What kinds of information about disabled people does the public need? The public does not need specific information about disabled people as much as it needs positive images about them. Positive images influence our perception of each other's humanity and our understanding of the commom thread that ties us together, disabled and able-bodied alike. What we don't know, we don't understand, what we don't understand, we often fear. Fear breeds prejudice and builds barriers. Portrayals of disabled people which show them coping with every day situations help foster an understanding of human bonds. This understanding can lead to the acceptance of disabled people as human beings with the same survival needs as any human being. Acceptance, in turn, can open the doors that provide entree into the mainstream of life: a job, a family, a home.

Lately, there have been a number of movies and television shows which illustrate how the mass media can be used to make the general public aware of the abilities and limitations of disabled people. Films of this nature go a long way in presenting the public positive images about disabled people as well as conveying a remarkable amount of factual information about specific disabling conditions.

It is obvious that our most effective means of reaching the public are the mass media. It is equally obvious that the key to accessing the media are the people who work in the media. They are the ones who should be the target of our dissemination efforts.

Let us now look at the dissemination of information to disabled people and their families. Some people are disabled from birth; others are disabled by a traumatic injury or disease. There are disabled people living in rural areas, urban areas, and suburban areas, some work in mainstream jobs; others in sheltered workshops; most are unemployed. Some reside in institutional settings; others live with their families and a growing number live independently or in group homes. Some disabled individuals have obtained the highest educational degrees, others have mental limita-

tions which may prevent them from attaining any degree. A large number of the disabled people in the world are illiterate.

The point is that there is no such thing as the disabled population as far as information dissemination is concerned. Where we live, whether or not we work and where, our educational background -- these are only a few of the variables which determine what we need to know and how we get our information.

The information needs of disabled people, unlike the other groups we have discussed, cover all life areas. They need to know about the nature of their disability and how to cope with the everyday problems of shelter, food, clothing, transportation, education, jobs, use of leisure time, medical care, making friends -- in brief, all the things that human beings need. Disabled individuals need to know about devices that can partially restore function and about services that can help them cope with their disabilities. Secondly, disabled people need information they can use to change the environment that further limits their ability to lead independent and productive lives. Because some disabilities limit the forms of information that can be received, alternate forms such as audio cassettes for those who are blind, must be provided to ensure equal access to information.

B. Dissemination Mechanisms

How do disabled people now obtain the information they need? As far as we can determine, there have not been any comprehensive studies on this subject in the U.S., or abroad. In developed countries, we may assume that disabled people obtain information from the mass media -- newspapers, radio, television. for more specific information about their own disability, they may obtain information from a service provider -- a doctor, nurse, therapist, or counselor or they may contact a consumer organization such as United Cerebral Palsy Foundation, the Association of Retarded Citizens and the like. But what about the millions of disabled people who live in remote villages with inadequate roads, much less radio or television, who can't read, and whose life styles have not changed substantially from generation to generation? Where we would disseminate a pamphlet on hygiene in the U.S., we might instead demonstrate such procedures in a village. Where we would use television and movies in developed countries, we might use stories and plays instead.

It is apparent that we know and are doing a great deal more to disseminate information to rehabilitation professionals than we are to disabled individuals and their families. The formal mechanisms we have developed to disseminate information to rehabilitation professionals have been designed primarily to support the service delivery system. There is a subtle but important difference between supporting the service delivery system and using it as a mechanism for disseminating information to disabled people. By that we mean using the service delivery system to distribute information products developed for disabled people, preparing service providers to more effectively play the role of information brokers, and generally enhancing the capability of the service delivery system as a dissemination mechanism.

III. International Information Exchange

Rehabilitation International began the examination of the problems of information dissemination in the early 1970's, sponsoring the first international meeting of experts on Communications in Rehabilitation in 1972 in the Federal Republic of Germany. Most recently, it has studied the problem together with University Centers for International Rehabilitation in 1979 and this section of the paper is a summary of the findings of the work of these two projects and of the experience Rehabilitation International has gained during the past decade of direction of international information services based in Heidelberg, New York, Mexico City and Stockholm.

Why exchange information internationally in this field?

The working assumption is that some commonality of success or failure of a program or activity is transferrable from nation to nation. Transfer can only take place with a sophisticated awareness of socio-economic and cultural frameworks or restrictions, but it can take place.

Example: Most of legislation concerning barrier free design in European nations and in Asia is based in part on the 1961 ANSI standard and on Swedish developed norms.

Example: Many countries have adopted or, subsequently, decided not to adopt the "Quota System" for employment of the disabled based on studies conducted in England.

Example: In many countries, the knowledge of national surveys of incidence of disability have precluded the necessity of expensive census taking or other basic research.

Example: American models of independent living programs benefitted in the early 1970's from Scandinavian examples and are now, after substantial adaptation to the U.S. situation, being studied by Scandinavian consumer groups.

What are the special problems of international information exchange?

Most information now being exchanged is done so between countries using the same language. The exhorbitant costs of translation and the dilemma of choosing what information to translate prior to certainty of its value mitigate against frequent use of translation.

The pronounced tendency internationally is for information exchange to take place among people who speak the same language.

Terminology, the specialized language of a particular field or discipline, presents even further obstacles. If static, terminology would present only a series of finite complications to be unravelled by the experts. But terminology evolves as one movement or approach puts another to rest. Shades of meaning are introduced and added as "dumb" becomes "mute" becomes "speech impaired," as "supported living conditions" become "independent living," as precise but demeaning labels are replaced by conceptual catch basins such as "learning disabled" or "developmentally disabled." It is little wonder that the field boasts no authoritative rehabilitation dictionary, as it would require as many supplements as the Oxford English Dictionary.

The lack of an internationally usable thesaurus greatly impedes the coherent classification of information within one language or among several. Comparative information on services, benefits, or costs is difficult or nearly impossible to obtain due to the multiplicity of specialized depots, and the use of non-parallel or incompatible methods of data classification, storage and retrieval.

The concept of a national disability information service, system or center is just beginning to find favor and is in incubation in the U.S., Canada, Spain, and Sweden and being planned in the Federal Republic of Germany, the Netherlands, and, to an extent, in England. With peer national information services of parallel intent, an international linkage system could follow somewhat naturally.

The development of truly centralized national information depots is, however, quite problematic due to:

* The tendency during the last decade of development of specialist national collections, such as, in the U.S., the Center for a Barrier Free Environment, Closer Look -- an information resource for parents of handicapped children, the Materials Development Center for vocational rehabilitation professionals; in England, the Center for Environment and the Handicapped, the Disabled Living Foundation specializing in aids and equipment and, recently, the series of DIAL (Disabled Information and Assistance Line), telephone information on benefits and resources. Many of these centers duplicate resources and their "national coordination" is at best a central index or directory of what is located where.
* Fairly well established turfs, creating a tendency to share or disseminate information of cosmetic value only.
* Increasing costs of information collection and storage, the introduction of electronic means, the introduction of highly trained specialized staff who can bridge the disciplines of rehabilitation and information science and the ever-increasing quantity of information in this field combine to produce a situation where only a serious commitment of funds and staff can lead to the establishment of a national information center. This level of funding is beyond the capability of voluntary organizations requiring the involvement of government. In a period of increasingly limited resources, many governments are finding it questionable to divert this level of funding from direct services. (Several national information centers have been stalled at the planning stage for years, awaiting funding.) In the meantime, the specialty centers have begun to develop trans-national linkages of their own. For example, the first international conference on establishing equipment and advice centers will be held in 1981.

What is the current pattern of information exchange internationally?

Rehabilitation professionals largely exchange information through the following methods: (in an estimated descension of frequency)

* International professional associations, (Appendix A) their conferences and published material.
* International Information Services, such as those operated by Rehabilitation International, International League of Societies for the Mentally Handicapped and the International Labor Organization (Appendix B).
* Peer linkages (formal exchange channels) among national centers or programs.
* Utilization of electronic systems with related internationally collected information, such as ERIC, MEDLARS, or **Excerpta Medica.**
* Fellowships or sponsorships of foreign study or other exchanges of personnel, including academic degree pursuance.

What new approaches are being tried?

Rehabilitation International, aware of the various complexities described thus far, of the different national situations and needs and of the necessity of testing out a variety of approaches, is sponsoring or planning the following experiments:

* The long established information center in Heidelberg, operated by R.I. in cooperation with the Stiftung, has developed into a comprehensive collection of information concerning Europe and the U.S. and Canada. Comprised largely of periodicals (approximately 500), plans are to concentrate on annotated bibliographic information exchanged through three or four peer centers via microfiche. Information would be made available to the public in the form of literature searches for a fee.
  Information would concentrate primarily on the scientific literature, published mainly by the developed countries. This approach takes advantage of the observers preference in Europe for the exchange of

highly specialized and scientific information between peer centers.

* To approach the particular Latin American situation where organized information publications, collection or dissemination is at a premium, the suggested initial program is to amalgamate the resources of several large organizations to:
  - Publish a periodical in Spanish of news of the major international regional and national organizations and to widely disseminate this free of charge.
  - Organize a selection of material in Spanish published in Spain and the U.S.A. for selected continuous distribution to 50 national resource centers in Latin Americ
  - Initiate a comprehensive regional collection of books, per. dicals, and reports published by Latin American groups concerned with disability, and organize their classification to enable responses to queries.
  - Provide brief training in information collection and dissemination for selected leaders in the disability field in Latin America. This approach realistically acknowledges the financial inability of most Latin American based disability concerns to publish or otherwise disseminate information on a regular basis and at the same time promotes regional identification by utilitizing the resources of several organizations based in several countries to initiate organized dissemination.
* Rehabilitation International is establishing with support from UNICEF and other sources an international resource and planning service that will bring together data about human and institutional resources as well as information materials needed for the development of programs and facilities for disability prevention and rehabilitation. Among the products of the service will be ideas and content for information materials designed to meet the special needs of developing countries.
* Rehabilitation International is discussing with the University Center for International Rehabilitation the possibility of collaborating in the compilation of information about various countries. Plans are in the most preliminary stages but it is hoped to locate funds to carry forward this experiment.

IV. Recommendations

A. For Rehabilitation Professionals

1. Formal mechanisms for disseminating rehabilitation information to professionals should be problem-oriented, rather than discipline based. Problem oriented mechanisms have the capability to provide the knowledge that bears on a specific problem regardless of its source or form. Such mechanisms can be made more effective if they incorporated in their design those features that make informal mechanism so effective: simplicity in use, rapid response, and assistance in formulating the problem and in interpreting the results.
2. The gap between research and practice can be narrowed by systematic efforts to repackage research results for specific audiences. What counselors need to know about independent living, for example, is not quite the same as what decision makers need to know about the same subject, or what researchers and educators need to know. The length, presentation, language, form and vocabulary differ with each audience. While appropriate mechanism used for counselors may be a workshop, decision makers may get a summary of a report where researchers may need a full report. Such repackaging efforts are costly and can only be done on a selective basis.
3. Rehabilitation professionals should be trained in the use of existing dissemination mechanisms, either as part of the formal degree program or provided as in service training. Their lack of awareness of existing mechanisms, much less the use of these mechanisms, has been documented repeatedly by numerous surveys of information needs. It is particularly important to include this subject in the graduate programs for foreign students.
4. Establishment of an **international hierarchical thesaurus.** A study carried out by the Stiftung Rehabilitation determined that English should be used as the base language, both because of its frequency of use and because of its structure. International classification of technical aids has been initiated by the Stiftung and by the Nordic Council on Disability. International vocabularies are being published by the International Labor Organization in the field of vocational rehabilitation and by UNESCO in special education. A key word system has been evolved by the Canadian Rehabilitation Council for the Disabled.
5. Publication of anthologies of "the best" literature on an annual basis, nationally and internationally. These literature collections, if published by authoritative sources, could serve as recommendations for translation. Anthologies of the most significant research, nationally and internationally, should be published annually or bi-annually, written in language for lay consumption, along the idea of "Rehab Brief's", the U.S. government's successful periodic summaries of important U.S. research projects, tailored for the rehabilitation generalist or specialist unfamiliar with "R&D idiom."
6. Identification of centers or initiation of centers whose responsibility it would be to assemble, classify, store and disseminate information which would characterize rehabilitation nation by nation. These centers would rely on the most active of the national information sources and be capable of producing country files which would reveal:
   - **What is working or not working where (nationally)**
   - **Who are the national experts on a particular subject**

- **Recommend centers or programs for foreign visitors, by specialty**
- **Comparative information on statistics, legislation and benefits**
- **Selected international bibliographies on topics of universal concern (a recommended mini-library)**

7. An analysis of how best international information can benefit groups other than rehabilitation professionals (see Appendix C for analysis of groups needing information about disability) such as parents of handicapped children, governmental authorities and disabled people.
8. A special program for developing countries involving establishment of national and regional library/information centers. Program should include provision of material and training for information specialists.
9. Increased focus on dissemination responsibility of all information producers, which should be reflected by grant requirements and pressure from major information producers.
10. Fostering of linkages between national information depots so that, gradually and naturally, these information channels are strengthened. A pilot project of linking two or three peer systems should be established to test out the various technological and terminological approaches.

B. For Disabled Persons and Their Families and the General Public

1. International action in this sphere should be perceived from the vantage point of advocacy with the objective of convincing relevant international professional organizations, national planning bodies and all national organizations and associations of the importance of involving disabled people and their families in the already well established professional information networks.
2. It should be possible to assemble an international overview on information needs of the family concerning disability with reports of outstanding services in various countries which have successfully involved the family in all aspects of the rehabilitation process and which have initiated outreach programs. The overview could include results of the international workshop on disability and the family to be held within the 1980 World Rehabilitation Congress, and other family conference papers.
3. Encouragement should be extended to all national organizations to hold interdisciplinary conferences on the family as focal points of rehabilitation.
4. Simple basic pamphlets concerning the handicapped, prepared by category of disability, should be published with the objective of their wide dissemination in developing countries, as well as developed. Pamphlets should include basic developmental information and therapeutic home-based activities, well illustrated with the lowest of literacy in mind.
5. In all countries, but particularly in developing countries, emphasis should be placed on the utilization of other media, such as radio, as outlets for regular family oriented information concerning disability. The focus should be on, primarily, what the family unit can do in isolation of professional assistance.
6. It is estimated that the lack of coherent information concerning disability and disabled people presented for the public through the media can be attributed to:

* Lack of sufficient information provided methodically or creatively by the disability related organisms.
  An attitude by the media producers which relegates coverage of disability to the medical department and which relegates reporting on disabled people to the "unusual and heart-rending feature" department.
* The underlying fears, mythology and negative attitudes towards disability on the part of the public and tacitly supported by the media (as evidenced by countless attitude studies).

Assuming that the last two are at least partly dependent on the first, it is strongly recommended that greater increased attention be given to the improvement and augmentation of information concerning disability provided to the media.

7. Research concerning utilization of the media as public education pertaining to disability should be gathered from various countries, including Canada, the U.S., France, England, Switzerland, Sweden and the Federal Republic of Germany, and published together with programmatic descriptions of the activities carried out.
8. International guidelines on the representation of disabled persons in the news media and other widely disseminated educational material such as textbooks should be adopted and given wide dissemination to media outlets.
9. Meetings should be held with media representatives to present statistical and other scientific evidence of disability as a major presence on the social and socio-economic scene of every nation. Requests should be made that coverage of disability and news and features concerning methods of society's need for adaptation to accomodate in a dignified fashion this segment of its population.
10. Consideration should be given to the establishment of national disability communication activities, coordinated expressly to avoid plying the media with thousands of scattered messages, designed to promote organizational activities rather than information about the causes and consequences of disability.

Summary of Elizabeth Pan

Information dissemination in rehabilitation has not been a focus of priority concern until recently. Information dissemination activities have been uncoordinated, resulting in duplication of effort as well as gaps in service. The proliferation of possible sources of information has created the general impression of an explosion of information in the field of rehabilitation. The explosion is not so much due to the rapid growth of knowledge in the field as it is due to the lack of effective mechanisms for synthesizing, cumulating and retrieving that knowledge as needed. This problem is compounded by the fact that rehabilitation is a multidisciplinary field and most existing mechanisms for information dissemination are based on a single discipline.

The majority of existing formal mechanisms for retrieving rehabilitation-related information are designed for rehabilitation professionals. These mechanisms are primarily print-oriented. Most of the literature in rehabilitation are not published in the mainstream of the book trade. Research reports, newsletters, conference proceedings, etc., are distributed to a very limited readership with no provision for their retrieval after the initial supplies of copies are depleted. Much of this "figurative literature" can be "saved" if existing generalized retrieval mechanisms such as libraries are used to ensure long term access to this literature. The potential role of the private sector, particularly in print and electronic publishing, has not been developed.

Dissemination mechanisms focused on rehabilitation are beginning to emerge all over the world but their effectiveness is limited by a lack of coordination and standardization in indexing language. Few professionally trained information scientist are involved in the design and operation of these mechanisms. It is the exception that dissemination are designed based on a clear picture of who the users are and what their information seeking habits are. Com munication among those involved in the design and operation of information retrieval mechanism is haphazard and u n f o c u s e d .

Dissemination of information to disabled individuals, their families and he general public is primarily the work of organizations which represent various segments of the disabled populations - veterans, blind people, those with cerebral palsy, etc. This segmentation of delivery of information tends to reinforce the differences among disabilities rather than their similarities. The millions of disabled people not reached through these efforts are reached by mass media -newspapers, popular magazines, television and radio - where such media exist. In the developing countries, basic information about health and nutrition can be disseminated through individuals, particularly families and community leaders.

The challenge of the 80's lies in our ability to use existing mechanisms for dissemination rehabilitation information more effectively by involving more professionally trained information scientists and training those who design and use these mechanisms. If we are to reach the millions of disabled people in both developed and developing countries, the service delivery systems in each country must be used to disseminate information.

Summary by Barbara Duncan

The information specialist, particularly in developed countries, is now in a position to advocate for change. Part librarian, part counselor, part encyclopedia, part systems analyst, the information specialist must now address the whole: taking the initiative in evaluating the mass of material now flooding the developed nations, helping to create structure awareness of the better material and developing methods to ensure dissemination of "the best of what we know" to those who need it in developing countries. This is our major challenge for the 1980's:

There is a need to initiate a new cycle of information flow, which will identify material of quality, direct its reformatting for audiences not in the information mainstream and taking pains, if necessary, to marshall the material to these sources. Dissemination strategies, their refinement and advancement, must be the emphasis for the 80's if we are to create a **useful** information flow and reach those who need our information the most.

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Appendix A

The United Nations and Its Specialized Agencies

Body	Dissemination Responsibility	Media Used	Current Examples
UN Center for Social and Humanitarian Affairs, Vienna Works closely with:	UN Family and National Planning Committees for International Year of Disabled People-1981	Meetings Newsletters	Currently, the center is to act as UN focus for planning for IYDP and to disseminate information regarding activities
UN Division for Social and Economic Information - DESI, New York	UN Family and public press and media	Press kit Posters Newsletter	Press kit for IYDP to be released January 1, 1981
International Labor Organizations, Geneva Vocational Rehabilitation Section	UN Family, labor departments of governments and labor representatives, field experts, advice to governments on request	Meetings/proceedings Print media information service (Blindoc), expert's field reports Booklets	With primary focus on assistance to developing countries in establishing national planning for vocational rehabilitation services and model centers, the ILO publishes basic booklets on the principles of this field and manual on planning centers and workshops, Meeting reports often contain summaries of VR country to country. Information on new legislation also published in a special legislative series
UNESCO Special Education Unit, Paris	UN Family, governmental, educational and cultural departments, governments on request	Meetings/proceedings Books Experts' reports from field	UNESCO books on the economics of special education, sports for the disabled, and comparative studies of special education generally contain national examples from different cultures and regions Assists governments in planning educational services for special groups
World Health Organization, Geneva Strengthening of Health Services Department	UN Family, regional and national WHO offices national health departments and other national bodies concerned with health, governments on request	Meetings Scientific and popular Journals Manuals Press releases Annual press kit on health topics	Current emphasis on disability prevention and simple rehabilitation techniques within primary health care scheme. Recently has sponsored several statistical investigations of disability incidence in developing countries. Has developed manual of basic principles of rehabilitation and international classification scheme of handicaps, impairments and disabilities. National immunization campaigns
UNICEF New York	UN Family, regional National UNICEF offices	Meetings Culturaivery systems in each country must be used to disseminate information.	Current emphasis on disability

International Non-Governmental Organizations Concerned With Disability

To coordinate the disability related activities of the UN, its specialized Agencies and 35 international disability related non-governmental organizations, the CWOIH (Council of World Organizations Interested in the Handicapped) was founded in 1953 and has held annual meetings since. The Secretariat for the CWOIH is provided by Rehabilitation International with financial assistance from UNESCO. The following CWOIH members, all in consultative status with at least one of the UN Specialized Agencies, disseminate information concerning disability. Rehabilitation International publishes a compendium of activities of CWOIH members every second year and regularly reports on members' conferences and other activities in the International Rehabilitation Review.

CWOIH Members

Organization	Dissemination Responsibility	Media Used	Special Focus and Current Examples
Boy Scouts World Bureau, Geneva	National member organizations	Conferences Newsletters Journals Posters	Promotes "extension scouting", scouting adapted for boys with disabilities, and scouting projects and activities on behalf of local institutions concerned with disabled and elderly
Catholic International Union for Social Service, Brussels	Membership organization and associations of Catholic Social Workers in 35 countries	Newsletter Journal	Promotes inclusion of curricula focusing on disability concerns in schooling of Catholic Social Workers
European Association for Special Education	Member association in 14 Western European	Meetings/proceedings Newsletter	Hold European seminars on all aspects of special education
European Alliance of Muscular Dystrophy Associations, Brussels	European members associations	Meetings	
International Association for Prevention of Blindness, Sussex, England	National committees in 50 countries	Conferences Press releases Professional articles in WHO journals	Works in conjunction with WHO in campaigns to prevent blindness particularly in developing countries
International Association of Workers for Maladjusted Children, Paris	National member associations and individual members in 38 countries	Conference/reports Pamphlets	Children with disabilities often included as topics of conferences
International Catholic Child Bureau, Paris	160 national member organizations	Journal	Specialized commissions and study groups on children with handicaps and their religious education
International Committee of the Red Cross Geneva	Swiss committee members	Journal Handbooks	Relief actions, setting up workshops, for manufacture of artificial limbs, equipment, on request from governments, usually in post-war emergency situations
International Confederation of Free Trade Unions, Brussels	National member organizations in 88 countries	Journals Newsletters	Occasionally sponsors seminars on labor market and workers with disabilities
International Council of Nurses Geneva	National nurses associations in 87 countries	Meetings Policy statements Journal, News releases	Promotes professional development of rehabilitation nursing
International Council of Societies of Industrial Design, Brussels	Member societies in 32 countries	Meetings Journal News releases	Has held international workshops and student competitions concern-industrial design solutions for people with disabilities
International Council on Social Welfare Vienna	Regional offices, member organizations and individuals in 70 countries	Meetings Journal Newsletter Reports	Promotes improved training of SOCIAL WELFARE WORKERS, Will hold European Regional Conference on Integration of Handicapped, July, 1981, France
International Diabetes Federation, London	National member organization in 54 countries	Conferences Journal	Circulation of new findings and information about diabetes a major objective
International Federation of Disabled Workers and Civilian Handicapped (FIMITIC) Olten, Switzerland	Members in 22 countries	Meetings/Proceedings Newsletter Press releases European Organizer of World Day for the Disabled, posters	Plans to organize international conference of disabled people in 1981. Operates advice and information bureau for members
International Federation of Multiple Sclerosis Societies, Vienna	National member societies in 22 countries	Public education seminar Abstracts of scientific findings	Holds conferences for public on various aspects Central information collection a major purpose

International Federation of Physical Medicine and Rehabilitation, Netherlands	Members in 34 countries	Seminars Manuals on education and training	Concerned largely with professional training of persons working in physical medicine and rehabilitation
International Hospital Federation, London	National hospital and health service organization	Conferences Journal	Design of hospital facilities and equipment for disabled a major theme of 1981 Congress, Sydney
International League of Societies for the Mentally Handicapped, Brussels	Nearly 80 member organizations in 60 countries	Congresses conferences/proceedings Newsletter	Information dissemination to professionals and families a major acitivity
International Social Service, Geneva	Member organization and correspondents approximately 110 countries		Focuses on assistance to individuals or families who have problems resulting from forced or voluntary migration
International Leprosy Association, Surrey, England	Members in 50 countries	Congresses Scientific journals	Promotes rehabilitation of persons with leprosy, focuses on developing countries
International Society for Burn Injuries, Scotland	Members in 80 countries	Scientific abstracts Journal Newsletter	Promotes reintegration into society of people with burn injuries
International Union Against Cancer, Geneva	National organization in 76 countries	Congresses, conferences seminars, Journals Newsletters, Technical reports, Monographs	Exists to promote informational exchange, particularly research results concerning cancer
International Union Against Tuberculosis, Paris	Members in 86 countries	Conferences/proceedings Newsletter	Promotes particularly key information concerning research
International Union for Child Welfare, Geneva	National members in 71 countries	Congressess, Journal Bibliographic citations Newsletter	Includes handicapped child as a major focus. Extensively reviews books, journal articles in this field on a regular basis
Rehabilitation International, New York	Member organization in 65 countries, 8 international member organizations and information service subscribers in 100 countries	Congresses Conferences/proceedings Journals, Newsletter, Posters, Pamphlets, Acquisition lists	Dissemination of information a major objective. Directs information services serving worldwide rehabilitation community, located in Heidelberg, Mexico City and Stockholm
Salvation Army, London	Officer, employees 79 countries	Popular magazines Pamphlets	Supports hostels, hospitals and other direct services for disabled
World Association of Girl Guides and Scouts, London	7.5 million members in 98 countries	Journals Manuals	Promotes both extension scouting and integration of scouts with disabilities into regular troops
World Confederation for Physical Therapy London	40 national member organizations representing 95,000 physical therapists	Conferences Newsletter Listings Comparative requirements	Maintains registry of physical therapists available for foreign service. Advises on development of physical therapy services
World Confederation of Organizations of the Teaching Profession Morges, Switzerland	123 national member organizations in 77 contries representing 5 million teachers	Conferences/proceedings Journal	Covers teaching of children with handicaps and special education in conferences and publications
World Leisure and Recreation Association, New York	Member agencies and individual members in 100 countries	Congresses, conferences/papers Newsletter, Booklets	Covers therapeutic recreation and recreation for people with disabilities in conference and publications
World Medical Association, Ferney-Voltaire France	National medical associations in 55 countries	Congresses, conferences/proceedings Professional journal Newsletter	Operates clearinghouse for doctors to locate information on medical matters in member countries Issues international medical codes and principles
World Union for the Safeguard of Youth, Paris	Member associations and individual members in 33 countries	European conferences/ reports, Newsletter	Handicapped children a frequent conference topic. Tracks bibliographic documentation on youth

World Veterans Federation, Paris	National member organizations in 49 countries representing 20 million members	Conferences, Studies Newsletter	Focuses on prosthetic and orthotic equipment provision and training courses in this area. Operates an information office on barrier free design. Recent conferences on media and handicapped, integration and legislation concerning war victims
World Young Women's Christian Association (YWCA), Geneva	National member associations in 80 countries	Journal Pamphlets	Many national member organizations sponsor programs (camps, recreation etc.)for handicapped youth
World Council for the Welfare of the Blind, Paris	Member organizations in 66 countries, 4 international members	Congresses, conferences/proceedings Newsletter Regional journals	Assists formation of national societies, collaborates with ILO in provision of Blindoc, information service focusing on provision of summaries of articles of practical usage for field workers concerned with blindness
World Federation for Mental Health, Vancouver, Canada	National member organizations	Congresses, conferences Film listings Newsletter	
World Federation of Hemophilia, Montreal, Canada	National member organizations in 55 countries	Congresses, conferences/ proceedings, Training centers, Scientific abstracts service, Pamphlets	Has recently established an international clearinghouse of non-medical information about hemophilic in association with Stiftung Rehabilitation, Heidelberg,Federal Republic of Germany
World Federation of Occupational Therapists Pretoria, South Africa	National member organizations in 26 countries representing 27,000 occupational therapists	Congresses/proceedings Recommended standards	Issues various papers on development of professional associations for OT departments; bibliographies and maintains information on exchange of occupational therapists among its member countries

CWOIH Associate Members

Organization	Dissemination Responsibility	Media Used	Current Examples
Leonard Cheshire Foundation, London	190 member foundations in 48 countries	Journal Films (by members) Books	Cheshire homes are non-institutional residential accommodations for permanently physically or mentally disabled, especially for the indigent. An international conference on establishing Cheshire homes is planned for 1981 in London
Goodwill Industries of America, Washington	40 affiliates in 29 countries (+ 167 in USA)	Conferences Newsletter	Provides advice and training in establishment of vocational rehabilitation programs. A current project is development of such programs in Africa and the Caribbean, with the assistance of the US Agency for International Development (AID)
International Bureau for Epilepsy, London	Member organizations in 41 countries	Conferences/reports Newsletter, Glossary Handbook	Promotes in particular public education concerning epilepsy, especially non-medical aspects. Maintains handbook of epilepsy centers internationally
Helen Keller International, New York		Conferences, seminars Wide range of publications for health workers, parents and professionals in field	Emphasis on blindness prevention in developing countries, training of blind adults in rural occupations and in mobility and independent living skills
International Cerebral Palsy Society, London	Members in 50 countries	Conferences Newsletter	Prevention of cerebral palsy is a current focus, with the "Save a Baby" campaign being initiated in 1981 through its member associations

International Committee Against Mental Illness, New York	Seminars	Includes as major goal: "Utilization and expansion of psychiatric data and information systems including computer technology, as a major tool in diagnostic treatment, rehabilitation and organization"

APPENDIX B

International Information Services in the Rehabilitation Field

--Examples--

Service	Sponsors or Agency Responsible	Services	Language	Description or Examples
Rehabilitation International Information Service, Heidelberg base	Rehabilitation International in cooperation with Stiftung Rehabilitation Heidelberg	Responds to queries Literature Searches of periodicals, reports Selected international bibliographies Quarterly mailings of selected publications	English German	Project based in Heidelberg since 1973. Bibliographies and quarterly mailings reflect priorities of RI program and specialties of Stiftung. Literature searches undertaken when other literature bases are inadequate. Primarily serves RI member organizations and libraries in developing countries
Rehabilitation International Spanish Language Information Service (SIDIR), Mexico City	RI in cooperation with the Inter American Institute of Social Security	Periodical mailings of newsletter and selected rehabilitation literature	Spanish	Currently under revision in cooperation with several other regional and national organizations involved in Spanish language information dissemination
International Information Center on Technical Aids, Housing and Transportation (ICTA), Stockholm, Sweden	Rehabilitation International in cooperation with The Handicap Institute of Sweden	Newsletter, Annual reports of RI ICTA commission members Occasional publications	English	ICTA's current program includes development of an international thesaurus on technical aids, an international research and demonstration project on communication aids for the speech-impaired and sponsorship of "Access to Skies" program
International Information Service on Mental Retardation (SIIS) San Sebastian Spain	Operated under auspices of International League of Societies for the Mentally Handicapped, supported in part by Institute of Social Services, Spain	Bibliographic journal, trimestial Literature searches, Books and booklets for professionals and parents, Annotated international bibliographies	Spanish	Since 1972 SIIS has been serving the Spanish speaking community involved in mental retardation and associated developmental disabilities. Its journal reviews in Spanish books and reports published in English and European languages and lists articles from the major professional journals
International Children's Center, Paris, France	UNICEF and Government of France	Journals, Acquisition lists, Subscriptions to receive tailored reference lists, Open library and photocopying services Training courses and seminars	French English	A current ICC project is to tailor health related information for varied audiences, including educators, media and selected groups of professionals. Sponsored by the U.S. Dept. of Health and Human Services, the project includes early intervention strategies and immunization campaigns as topics for analysis. The handicapped child is a major topic of the ICC collection, particularly in the French language

APPENDIX C

National Information Centers/Services Concerned Primarily With Disability
(Other than the United States of America)

Center/Agency	Parameters/ Outreach	Services	Comments
Canadian Rehabilitation Council for the Disabled, Toronto, Canada	The generalist agency interfacing between government and voluntary sectors. Most national and some provincial associations in field are members of CRCD	Conferences/reports Journal, Newsletter Films, Public education campaign-all media Response and referral system for inquiries Library pamphlets	CRCD has on-going project to index national, provincial and special information resources in field. Has published directory of these resources 1979. Published key-words in field in English and French together with librarian's manual on establishing resource center. On-going all-media campaigns on attitude change, prevention. Highly successful award winning "spots" produced for campaigns
Center for Environment and the Handicapped, London, England	Intended audience: professionasl involved in architecture, design or planning and students, as well as general rehabilitation community. Scope includes environmental barriers to physically, mentally and sensorially handicapped	Seminars/reports Journal. Inventory of British "successes" in planning of public buildings and facilities purpose-built for handicapped. Advice/technical consulting service for architects. Occasional papers	CEH specializes in re-packaging information concerning barrier free design for design and architecture professionals and does this via a series of small seminars and early consultations with planners and builders and the design stage. Unique aspect of this center is its equal attention to supportive environments for mentally handicapped
Disabled Living Foundation, London England	Originally and still largely concerned with collecting, classifying and dissemination of information on aids and equipment to local governmental authorities (the major purchasers), organizations and disabled individuals. Scope has expanded somewhat to activities of daily living	Subscription service of announcements and descriptions of technical aids, training courses, and related publications. Training courses and seminars. Booklets resulting from special projects. Publications related to its projects -- acts as sales agent	Disabled Living Foundation has trained founders of its Welsh and Scottish counter-parts. Is considering providing training for other founders of information centers. Has served as an international model studied by Australian, Canadian and U.S. information specialists
Netherlands Society for Rehabilitation, Utrecht, Netherlands	National organization newly revised to represent main national organizations of and for the physically handicapped	Conferences, Exhibitions Journal, Information service responding to queries. Popular articles written for magazines of various professionals. Advice and guidance service on barrier free design	The Netherlands Society is the responsible national office for centralization of general information on barrier free design transportation and the International Symbol of Access, as well as physical disability in general. Recently reorganized information in response to queries Actively searches out professional journals (builders, sports officials, etc.) to carry articles on that topic relation to disability concerns. Tracks information on holidays, publishes with national tourist office.
Belgium Red Cross Society, Brussels, Belgium	In addition to usual Red Cross concerns, responsible office for information on technical aids, daily living activities and barrier free design for French speaking Belgium. Primarily interacts with governmental authorities and professionals, especially occupational therapists	Conferences/seminars Newsletter Technical aid sheets-series. Pamphlets Permanent comprehensive display center of technical aids and equipment Tapes about new technical aids distributed to the home bound. Films on new aids	The Society operates an advice and guidance network of (largely) volunteers who are professional occupational therapists and who disperse information and guidance to disabled individuals within their locales. Has developed a classification system for technical aids in French. Recommends importation of new aids based on knowledge of Belgian and European markets

Institute for Social Services (INSERSO), Documentation and Publications Department, Spain (Comprising rehabilitation of physically, mentally, sensorially disabled elderly and those impaired by alcohol and drugs).	Governmental office within newly organized department of Health and Social Security. Responsible for information dissemination to all government offices and direct service centers operated by government. Also in direct touch with major voluntary organizations	Conferences/reports Journals, popular and scientific. Books on basic aspects of rehabilitation (e.g. prevention, mental retardation) statistics TV and radio programs of information for disabled. Public Education campaigns--print media, posters. Library--responses to queries	INSERSO collects and classifies books, documents and periodicals literature on all aspects of disability with some emphasis on international references. The majority of its books and articles are translated from or derived from English or French texts. The documentation department has links with centers in Latin America and has expressed interest in expanding assistance to dissemination of information in this region. Cooperates closely with SIIS--see International Centers
Scottish Information Service on Disability department of Scottish Council on Disability Edinburgh, Scotland	Non-profit organization responsible for information dissemination to governmental departments, local authorities and voluntary groups in field	Conferences/Newsletters Scottish branch of Disabled Living Foundation--providing subscription service of technical aid sheets, other information. Mobile van of equipment, books, information materials	Encourages growth of network of local information centers known as "DIALS" (telephone inquiry services). "MAC", the traveling van of equipment and information is staffed by occupational therapists and tours the rural inaccessible parts of Scotland year round
The Swedish Institute for the Handicapped, Stockholm (Bromma) Sweden	Reports to Government of Sweden and Federation of (23) Swedish County Councils Responsible for research development, testing and information within the field of rehabilitation technology Statute requires Institute to "observe" international achievements and cooperate within this field with institutions outside Sweden	Storage of reference items on blind, deaf, speech impaired on computer tapes. Selected dissemination and also available by subscription. Journals (Swedish/English). Inquiry service by telephone and correspondence. Research findings. Occasional technical papers. Comprehensive library on all aspects of handicap, international emphasis	Swedish Institute, home of ICTA (see International Information Services) is long-established leader in international collection and dissemination of information on the technical side of handicap: aids, equipment, housing, transportation and their respective terminologies. Participates actively in Nordic meetings of similar bodies. Participates in shared research projects of Scandinavian countries. Probably houses world's most comprehensive international library on handicap
Mulhouse Rehabilitation Center, Mulhouse, France	Distributes information to vocational rehabilitation concerns nationwide and interacts with 25 or so other centers chosen by the European Economic Community to establish communication and joint research as model demonstration centers	Conferences Seminars/reports Bibliographic (annotated periodical on primarily vocational rehabilitation Microfiche storage and retrieval system	Evaluates documents, books, periodicals for information for two audiences: internal and external vocational rehabilitation community and internal population of 400+ rehabilitation clients of the Center. Offers information services to clients, utilizing traditional library and microfiche
National Institute on Mental Retardation, Ontario, Canada	Intended audience is professionals, parents and those involved in mental retardation services. Scope includes advocacy as well as information provision.	Seminars journals, manuals for professionals	The NIMR has initiated basic strategies for evaluation of services in this field, which have been adapted by other countries and basic manuals on mental retardation, in wide use internationally.

APPENDIX D

U.S. National Sources of Rehabilitation Research Information

Name	Address and Telephone Number	Purpose
AAHPERD/IRUC	1201 16th Street Washington,D.C. (202) 833-5547	Provides a noncomputerized data base on physical education, recreation, sports for handicapped individuals. It is updated monthly.
Accent on Information (AOI)	P.O. Box 700 Bloomington, IL 61701 (309) 378-2961	A computerized retrieval system operated by Accent on Living, Inc. to help persons with disabilities live more effectively by providing them with information relevant to specific problems.
Adaptive Systems Corp.	1650 S. Amphlett Blvd. Suite 317 San Mateo, CA 94402 (415) 573-6114	Provides a time-shared computer-based system which lists manufacturers and available items. This system is called ISARE (Information System for Adaptive and Rehabilitation Equipment).
Clearinghouse on the Handicapped	Office of Handicapped Individuals. Department of Education Switzer Building Washington, D.C. 20202	Collects descriptions and addresses of national, state, and local organizations that supply information about handicapping conditions. Refers individuals to relevant information providers in the public and private sector.
Educational Resources Information Center (ERIC)	(Central ERIC) National Institute of Education Washington, D.C. 20208	Nationwide information system designed to provide access to documents, unpublished manuscripts, books, professional journal articles and writings on the subject of education through a network of sixteen ERIC Clearinghouses.
Excerpta Medica	P.O. Box 3085 Princeton, N.J. 08540 (609) 896-5450	International organization established to make information available to medical and related professions on all significant basic research and clinical findings reported in any language, anywhere in the world.
Experimental Center for the Advancement of Invention and Innovation	University of Oregon College of Business Administration 131 Gilbert Hall Eugene, OR 97403 (503) 686-3326	Provides low-cost evaluation of new inventions and ideas as well as access to market and investment information. Three other centers are developing at the University of Utah, Carnegie-Mellon University and the Massachusetts Institute of Technology. These centers are funded by the National Science Foundation
Georgia Information Dissemination Center (GIDC)	Computer Center Boyd Graduate Studies The University of Georgia Athens, GA 30602 (404) 542-3106	Provides current awareness and retrospective search services for college and university staffs, government agencies, and industrial organizations.
IMPART	Texas Rehabilitation Commission 118 E. Riverside Dr. Austin, TX 78704	Innovative matching of problems to available rehabilitation technology functions as an individualized problem-solving service with the assistance of rehabilitation engineers and computerized research files.
Information Exchange Program	Arkansas Rehabilitation Research Center, University of Arkansas and Arkansas Rehabilitation Services 346 North West Avenue Fayette, AR 72701	Publishes a variety of directories and newsletters including: A research directory of the Rehabilitation Research and Training Centers, publications and audiovisual aids, and directory of the Rehabilitation Research and Training Centers, the Informer
International Cancer Research Data Bank (ICRDB)	National Cancer Institute Blair Bldg., Room 114 8300 Colesville Road Silver Spring, MD 20910 (301) 427-7150	Gathers, abstracts, and indexes information on current cancer research worldwide. Strives to increase the transfer of research information among cancer researchers.
Materials Development Center (MDC)	Stout Vocational Rehabilitation Institute, University of Wisconsin-Stout, Menomonie, WI 47551 (715) 232-1342	National central source for collection, development, dissemination of information and materials in the areas of vocational evaluation and work adjustment.

National Aeronautics and Space Administration (NASA)	Technology Utilization Office 600 Independence Ave., S.W. Washington, D.C. 20546 (202) 755-2420	Operates a network of seven, university-based Industrial Application Centers. These centers provide access to over 10 million documents. NASA also publishes useful source documents such as Technologies for the Handicapped and the Aged
National Burn Information Exchange (NBIE)	Michigan Burn Center University of Michigan, 909 East Ann Street Ann Arbor, MI 48104 Program Development Officer: M. James (313) 769-9000	National Burn Information Exchange is part of the National Institute of Burn Medicine. NCIE publishes a bibliography and various other information resources.
National Clearinghouse of Rehabilitation Training Materials	Oklahoma State University 115 Old USDA Bldg. Stillwater, OK 74074 (405) 624-7650	Gathers and disseminates rehabilitation training materials and information.
National Clearinghouse on the Handicapped	Office for Handicapped Individuals Switzer Building Washington, D.C. 20202	The OHI Clearinghouse serves as a central information resource by responding to both telephone and written inquiries. It has also developed several lists and guides such as Annotated List of Independent Living Centers, Directory of National Information Sources on Handicapping Conditions and Related Services.
National Rehabilitation Information Center (NARIC)	308 Mullen Library The Catholic University of America Washington, D.C. 20064 (202) 635-5826	NIHR funded to organize and make available comprehensive collection of documents and non-printed materials generated by NIHR grants and contracts.
National Spinal Cord Injury Data Research Center	Good Samaritan Hospital 1130 E. McDowell Road Suite A6 Phoenix, AZ 85006 (602) 257-2000	The Center has four principal activities: (1) Collection of standardized data for the 14 model SCI projects; (2) Analysis of that data; (3) Dissemination of materials; and (4) Documentation and promulgation of the concept of model SCI centers.
U.S. President's Committee on Employment of Handicapped	Washington, D.C. 20210 (202) 653-5044	Provides extensive and varied publications to disability community nationally and internationally, including journals, bibliographic materials and topical reports. Implements public education campaigns nationally.
Sensory Aids Foundation	399 Sherman Ave., Suite 4 Palo Alto, CA 94306 (415) 329-0430	Provides assistance to blind or partially blind individuals in locating sensory aids to facilitate employment.
Trace Research and Development Center for the Severely Communicatively Handicapped	314 Waisman Center University of Wisconsin 1500 Highland Avenue Madison, WI 53706	Trace Center information services include: (1) Resource Update Service--Annual subscription $5.00 provides current data sheets for insertion into Resource Book; (2) Reprint service; (3) National Workshop Series; (4) International Co-op Newsletter "Communication Outlook"; and (5) Nonvocal Communication Resource Book.
University Centers for International Rehabilitation (UCIR)	D-201 W. Fee Hall Michigan State University E. Lansing, MI 48824	NIHR-funded research, training and dissemination project designed to transfer information, including that emerging from research, from other countries to the United States and vice versa. Provides publications and specially tailored consultant and information retrieval services to those seeking information about what is going on in other countries.
Veterans Administration	Office of Technology Transfer 252 Seventh Avenue New York, NY 10001 (212) 620-6659	The Rehabilitative Engineering Reference Collection is available for use to professionals in the medical and allied health and engineering fields. It is over 25 years old focusing primarily on prosthetics and sensory aids. It contains books periodicals, technical reports, reprints, patents and audiovisual materials.
Veterans Administration	Market Center Hines, IL 60141 (312) 681-6820	The VA Marketing Center is the central procurement agency for medical supplies for all VA Hospitals. It is in the process of developing a handicapped directory listing all suppliers of devices for the handicapped. Provides quarterly publication on new products including devices, aids and equipment. Plans are underway to computerize this information.

Excerpts of Reviews and Comments

The following are excerpts of reviews, comments and questions raised by the Switzer Fellows. These are presented to further stimulate thinking as well as action as it relates to the content of the fifth chapter by Dr. Elizabeth Pan and Ms. Barbara Duncan.

"There is a need to develop further the suggestion put forth by Pan and Duncan that the service delivery system be utilized to a greater degree to distribute information to disabled people and to prepare service providers to more effectively play the role of information brokers. It would appear that few state rehabilitation agencies assume responsibility for providing generic non-vocational information in any systematic manner to its clientele. District offices, for example, have little print or non-print materials on subjects of general concern to disabled persons or their families. Much useful public interest information of general utility could be acquired or produced and made available to clients and their families. This is not to suggest that rehabilitation counselors are not a source of information - indeed, they are -but usually the information is conveyed informally in counseling and coordination of service and is not financially supported as an important agency service. Somehow agencies fail to recognize information products as a 'service' thus such services tend to be the first eliminated during cost conscious times.

The research-to-practice transfer in rehabilitation remains a difficult problem. After an all too brief and under financed effort at 'Research Utilization' several years ago, little has been done of late except to lament, 'curse the darkness' and engage in rhetorical fault finding debates between researchers, practitioners and educators. While it may be beyond the scope of this seminar, the state-of-the-art of knowledge transfer - between nations and specifically within the U.S. rehabilitation community - cries out for renewed study and the design of effective strategies and techniques.

While it is indeed important to disseminate, analyze and evaluate policy related research, the larger issue may be that pitifully little policy research is being conducted by rehabilitation professionals. The formulation of rehabilitation legislation and policy over the last few decades was largely the product of political negotiations and political influence - largely in the absence of data or analysis. Indeed, it is fair to say that the U.S. has no national policy regarding disability and rehabilitation."

--Donald E.Galvin, Ph.D.

"This is an excellent presentation of what we have and don't have in the U.S. in rehabiliation literature and the means of dissemination. Of particular interest are the implications for international exchange. While there are many examples of ideas going back and forth across the Atlantic Ocean where economic and educational levels are somewhat similar, this is less true with regard to exhange with the countries of southern and eastern Europe and the whole developing world. The paper lists several valid reasons and makes pertinent recommendations.

Of special value are the appendices which offer annotated lists of: United Nations Agencies, International Non-Governmental Organizations Concerned with Disability (CWOIH Members), examples of International Information Services on Rehabilitation and National Information Centers Concerned with Disability, and U.S. Sources of Rehabilitation Research Information."

--Jeanne R. Kenmore, Ph.D.

"The authors highlight the concern that there is limited information on the whole topic of rehabilitation. They also make the point that most of the needs for the professional and consumer alike, in terms of research, literature and information, have **not** been met. The reader is then left with a keen interest in having more specific recommendations on possible solutions suggested, based on the reality of **limited resources**, as well as ideas on how to better utilize and disseminate information that is **already** available. The examples in the Appendix are obviously valuable, yet how can the individual best utilize these sources? How, in fact, could some, if not all, of the knowledgeable groups listed, work together to expand their capabilities. One is also left with the idea, that in terms of needs, it could appear that involving more persons with disabilities could **expand** the capabilities of existing institutions, as well as creating new employment opportunities.

Throughout the paper there is a strong emphasis on the use of technology as a means of information. The reviewer questions how realistic this approach is, as it is not clear what the commitment of either the federal government or the private sector is to expanding existing capabilities nationally or internationally?

The whole issue of information dissemination should be proposed to the newly-formed **U.S. Council Institute for New Challenges** (U.S. Inc.)* for consideration as one of the 'major challenges for the '80s.' "

**The U.S. Council Institute for New Challenges was formed in late August, 1980, as one of the three major programs of the U.S. Council for the International Year of Disabled Persons.*

--Mercedese M. Miller

"In information dissemination a more activist approach targeting non-rehabilitation organizations and individuals as recipients of information concerning disability prevention and rehabilitation is required. Non-rehabilitation adminstrators, planners and policy makers in all fields need additional information about disability and disabled persons for adequate decision making. In developing countries, this would include personnel in the key ministries of planning, labor, education as well as social welfare. In international assistance agencies such as AID for example, this would include personnel in the Bureaus of policy and planning, development support and the office of the administration.

Another category of recipients of rehabilitation information dissemination needs to be delineated in addition to the rehabilitation professionals, and disabled persons/families/general public identified by Pan and Duncan. This category would include all those organizational entities who work, or should be working in partnership, in collaboration with rehabilitation entities. Local community groups such as churches, YMCAs, boy/girl scouts, service clubs, businesses, chambers of commerce, labor unions; political parties, national associations, international development assistance agencies all represent partners in the quest for helping disabled persons in developing countries survive --and all require information to be able to do so."

--Robert B. Ransom

"We have all experienced difficulty in obtaining needed information. Often, existing information is highly unreliable which increases the difficulty of obtaining it. An example would be trying to establish the number of people with disabilities which substantially limit their activities within the U.S. Yet, in developed nations today, we are innundated with information, much of it highly suspect. The rapid growth of communciations media in developing nations is swiftly leading them to the same point of saturation. The authors identify the need for information in a form other than print - i.e. video-tapes, slides, films. In our era of television, is print media becoming less valuable? There are some indications, through studies, that information as "entertainment" (video-tape, film, etc.) is more easily digested and more lasting in impact than print.

ISSUES FOR FUTHER DISCUSSION. Given the language problems and the lack of common terminology for disability related issues, has print become obsolete in the international sharing of information? Given the fluidity of the English language and the dangers of over mystifying disability, would a thesaurus of disability terms be useful? One of the present cautions in sharing information about disability is the hyperbole of so much of the statistical data available.

Each nation has its own unique method of disseminating information. All have schools and universities in common. I was surprised that the importance of disseminating information through the schools on disability was not stressed by the authors. Grammar/high schools are central sources of information for the general public including disabled people and their families. Universitites are major sources of information for professionals including doctors and teachers. The United Nations could resolve that this information (prevention, rehabilitation, integration) concerning disability be made available through schools at all levels of instruction.

RESEARCH IMPLICATIONS. What are the sources of information available to disabled people? In the United States, in the lower socio-economic areas, the major sources of information are ministers, doctors and teachers. How can these groups be better informed about disability and the sources of assistance available? How useful in the dissemination of needed information are such mechanisms as professional organizations meetings, exchange visits and textbooks? What are the key points of information in developed and developing nations?"

--Robert H. Ruffner

Summary of Recommendations

The following is a brief summary of the recommendations and the implications for action as developed by the Switzer Fellows as it relates to the topic of the fifth chapter. (The recorders were Dr. Elizabeth Pan and Ms. Barbara Duncan)

General Conclusions

(1) During the past decade we have witnessed an increasing emphasis on information services in this field, usually understood to comprise three functions: collection, classification and dissemination. The paper, coauthored by Pan and Duncan, cited the existence of numerous single disability or topic collections (blindness, architectural barriers) both international and national in scope, in approximately 20 countries, and reported the growth of national general listings (covering all disabilities and topics) in several countries as a trend.

(2) It was felt, that particularly, in developed countries, the time had come for information specialists to take the initiative in affecting creative dissemination techniques and to leave the more passive tasks of collection and classification to the more than able librarians.

(3) The problems could be reduced as follows, as they relate to **developed countries:**

a. Reflecting on the information explosion in general, **too much** "information", mostly unevaluated and in esoteric language, flows from one desk to another.

b. Information is generated largely by and for the professionals, leaving parents and disabled people with little access to practical information.

c. Reflecting the technological developments in general, rehabilitation information systems are gradually being placed on computers or within other expensive systems, ensuring that access to this information becomes progressively elitist, however efficient in its retrieval, storage and dissemination.

Related to developing countries:

a. Information collections in this field are largely medically oriented small in size and consist primarily of textbooks. They're located at the few rehabilitation centers or universities and are relatively inaccessible to the public, parents, disabled people or others in the field.

b. There are few professional publications in circulation of any significance.

c. Information about disability, either practical or theoretical, if in existence at all, is to be found in capitol cities, while 90 percent of the population resides in rural villages.

Each issue or problem area is indicated below along with some practical recommendations for action. The issues apply to developed and developing nations.

Issues Most of the existing formal mechanisms for disseminating rehabiliation information to professionals- are based on a single discipline and reach only those who work in that discipline. Because rehabilitation is a multidisciplinary field, relevant information exists in scattered sources, making retrieval difficult.

Action Formal mechanisms for disseminating rehabilitation information to professionals should be problem-oriented, rather than discipline-based. Problem oriented mechanisms have the capability to provide the knowledge that bears on a specific problem regardless of its source or form. Such mechanisms can be made more effective if they incorporated in their design those features that make informal mechanisms so effective, e.g., simplicity of use, rapid response, and assistance in formulating the problem and in interpreting the results.

Issues A great deal of research knowledge does not get translated into practice that can improve service - delivery because such knowledge is not communicated to practitioners in an effective manner.

Action The gap between research and practice can be narrowed by systematic efforts to repackage research - results for specific audiences. What counselors need to know about independent living, for example, is not quite the same as what decision makers need to know about the same subject, or what researchers and educators need to know. The length, presentation, language, form and vocabulary differ with each audience. While the appropriate mechanism used for counselors may be a workshop, decision makers may get a summary of a report where researchers may need a full report. Such repackaging efforts are costly and can only be done on a selective basis.

Issue Relevant information exists in many sources, but are often missed because of a lack of familiarity - with these mechanisms and their use.

Action Rehabilitation professionals should be trained in the use of existing dissemination mechanisms, - either as part of the formal degree program or provided as in-service training. Their lack of awareness of existing mechanisms, much less the use of these mechanisms, has been documented repeatedly by numerous surveys of information needs. It is particularly important to include this subject in the graduate programs for foreign students.

Issue Given the large number of disabled people who are not getting the information they need even if it - exists, it is not feasible to design a monolothic dissemination mechanism that can reach them.

Action Where mass media infrastructures exist, they should be used to supplement more specialized dissemination mechanisms. The service delivery system in each country should be used to disseminate the most basic information needed by disabled people.

Reviews and Comments from International Rehabilitation Experts

The five "Action Papers" (described as chapters in this monograph) were sent to rehabilitative and health care experts in every continent. Of the twenty-two papers sent out to be reviewed by these experts, seven have thus far returned in time for inclusion in this monograph

The following are excerpts of reviews and comments by persons from different countries or those representing a number of countries.

A Review of "Institutions for Disability, Prevention and Rehabilitation" (By Norman Acton)

Reviewed by: G. Onoaguluchi, Consultant Physician
University of Nigeria Teaching Hospital
Enugu, Anambra State, Nigeria

Mr. Acton has taken a hard look at the handling of the problems of the disabled in the world in general. He emphasized the fact that two Rehabilitation International Conferences have been held in the past in 1971 and the other, in 1978. At the 1978 Manila Conference a call was made for the establishment in each developing country of a national council for the welfare and rehabilitation of the disabled. The 14th World Rehabilitation Congress at Winnipeg in June, 1980, went as far as recommending that each country should have a minister for the disabled directly responsible to the Head of State or Government.

Mr. Acton's paper discussed the problems inherent in the establishment of centralized institutions for the welfare and rehabilitation of the disabled. He wondered whether such centralized national organizations would be best suited for tackling the problems at the local levels in such a way that each community has a feeling of being a part of the organizational set up. He also was not sure of the cost-effectiveness of such centralized organization.

In order to understand the issues involved, Mr. Acton presented a brief situation report about what obtains in a number of countries (mostly the developed ones). There is, unfortunately, a notable absence of any mention of the situation in Africa. Fortunately, however, a recent publication by James Burress, of the People-to-People Committee for the Handicapped in U.S.A.[1], has surveyed the action plans for and practices in disability rehabilitation in various countries in Africa including Nigeria, Ghana, Kenya, Tanzania and Uganda.

It is clear that in Black Africa over one percent of the population suffer from some disabling handicap. Recently the Federal Minister of Health in Nigeria, Mr. D.C. Ugwu, in laying the foundation stone for a $30 million National Eye Centre in Kaduna, Nigeria, announced that about 800,000 Nigerians are blind.[2] This in effect means that one out of every 100 persons in Nigeria is visually handicapped, but Nigeria has less than 100 medical specialists in opthammology to tackle the problem of blindness and other major eye diseases! This lack of manpower resources to tackle the rehabilitation of the disabled is not confined to the blind. There are great shortages of trained personnel in other areas of disability rehabilitation. There are inadequate numbers of physical medicine specialists, limb fitters, audiology experts and even specially trained teachers to teach the handicapped child. Only two universities in Nigeria - the University of Jos and the University of Ibadan - have programmes for training elementary school teachers in special education but between the two universities, less than 200 special education teachers are produced annually.

There is no doubt that in Africa, the problems posed by the disabled are stupendous. The situation in Nigeria is better than those in many other Black African countries but even in Nigeria the national plan for tackling the problems are rudimentary and fragmentary. Many disabled persons are still living as street beggars, and will continue to live as such for many decades to come unless there is a world wide concerted effort to assist these developing countries with the provision of men and materials for the rehabilitation of the disabled, and the institution of crash programmes for training nationals in all aspects of rehabilitation of the disabled.

There is certainly a general awareness in Black Africa of an urgent need to help these disabled people and it is my view that in celebrating the International Year of Disabled Persons in 1981, appropriate World Bodies and Agencies should endeavor to usher in new hopes for the disabled in the developing countries.

References

1. Burress, J.R. 1980. Developments in Services for Handicapped People. Africa, A Project Report. People-to-People Committee for the Handicapped. Washington, D.C. pp 218.

2. **Daily Times**, Nigeria, November 3, 1980. p. 1. "More Nigerians Go Blind, 800,000 cases now recorded."

A review of "The Prevention of Human Disabilities" (By Michael Marge, Ed.D.)

Reviewed by: M. Thangavelu, Regional Advisor
World Health Organization, Regional Office for Southeast Asia
New Delhi, India

My overall impression of the paper is that the sections recommending "Specific Procedures for Instituting a Comprehensive Prevention Programmme" is very good for formulation of policy, plan and programme development. If this paper is to benefit the developing countries also, then the introductory part dealing with prevention, categorization of disabilities and potential contribution of the ten major primary and secondary prevention strategies need editing by qualified professionals with considerable experience in the field of disability prevention and rehabilitation based on the morbidity patterns prevalent in any particular social environment.

The special strength of this paper as mentioned earlier lies in the pragmatic recommendations for a community-based approach towards disability prevention and rehabilitation.

These recommendations would indeed be useful for promoting development of this programme in the countries of Southeast Asia.

The Southeast Asia Regional Office, New Delhi, organized a number of Inter-Country meetings which resulted in formulation of a medium-term programme for the countries of the Region. We are collaborating with the Member States in the implementation of the activities on a time schedule. The main constraints we face are in terms of manpower and financial resources. However, it is gratifying to note that the community response for this programme is very good and we are hopeful of attaining at least 75 percent of the target. Since 1981 has been declared as International Year of Disabled Persons, we hope to accelerate development in this programme area based on governmental and commuity awareness created during this period.

It was noted that a report of the proceedings of WHO Inter-Country Seminar held in Solo, Indonesia, in December 1978, gives the details of current national activities and a plan of action for disability prevention and rehabilitation.

Reviewed by: Marian Weiss, M.D. Professor and Chairman
Medical Academy in Warsaw, Department of Rehabilitation at Konstancin
Warsaw, Poland

Dr. Weiss found this paper well-prepared and very comprehensive, but noted that it dealt mainly with primary as well as secondary prevention. She felt that, "we cannot, in rehabilitation, concentrate on primary prevention as it is enough to prevent disability should an impairment occur."

While Dr. Weiss believes that every effort must be directed to combat and prevent disability, the recommendation of an all out thrust at primary prevention cannot be accepted in Poland at this time.

Reviewed by: (Mrs.) V.U. Ezejiofo, Principal Social Welfare Officer
Government of Anambra, State of Nigeria
Enugu, Nigeria

No attempt was made to discuss direct implementation of service. The discussion was based on a developed country model and not on a developing country model. As you are aware in Africa through social and economic uncertainty, plus limited educational and developmental opportunity for the masses of its people, require a more practical description and measurement of models of services to be used.

I undoubtedly agree with the community-based program which is more decentralized but I strongly feel that a proper view of results are necessary for immediate change if necessary,. The problem is that we hold programs too long before evaluation. Therefore, programs must not be generalized. For example, 'Immunization is the most effective tool in prevention of infectious disease.' But in some parts of Africa, you are required to provide planned counseling to convince a greater population of the masses that such a program is necessary. Some of the conditions we may ignore will come to be social problems in other parts of the world and may influence program adversely, although some of these programs can be seen as procedual steps that are requisite for a more encompassing planning activity."

A review of "Assurance of Necessary Services and Support Systems" (By Susan Hammerman)

Reviewed by: Dr. B. Sankaran, Director General of Health Services
Nirman Bhavan, New Delhi, India

1. There should be a reference to the mortality due to Measles and the relationship between the developed and developing countries. A reference should include the steps that have been taken by the various developing countries for adoption of a national commitment for the attainment of Health For All by the Year 2000. Though this might look like a distant dream, many developing nations with a great deal of self-reliance and self-determination have set targets and goals for such an achievement.

2. In the case of disabled people, sample survey studies have been started in some developing countries to identify the problems that they have to contend with and it has been included in the forthcoming Census Operations. The exact number of physically and mentally disabled in the developing countries would have to be correctly checked up. The figure of 350 million would include probably all handicapped including physical, mental, visual and hearing.

3. The difficulties that arise in inflation, recession, decreasing purchasing power of the hard-earned rupee or dollar, loss of productivity by workers as a result of disability, inadequate economic benefits as a result of disability, poor labour laws and inadequate coverage of temporary labour are a part that affect many segments of society among the developing countries particularly where rapid industrialization has taken place with inadequate safeguards for protection of the workers. In this, a mention should also be made of the high incidence of traffic accidents in many large cities in the developing countries resulting in crippling for life of many workers and wage earners which increases to a large extent the number of physically disabled in large areas of the developing world. The contributory factor of increasing trends of alcoholism must also be brought out since this is a preventable factor. The existence of the **fourth world** among the urban slums in the partially developed and developing countries can also be mentioned. The recent urbanization with large scale migration for purposes of work has reduced many large cities in the developing world (e.g., Mexico City, Bombay, etc.) into areas where the situation is much poorer than among the rural poor with many of the problems that have been listed above.

4. The incidence and relation of disability due to inadequate nutrition, birth injuries, infections and accidents have been adequately emphasized. But besides this, one of the major factors is the low birth weight of the child in almost 30-35 percent of births among developing countries resulting in a higher infant mortality rate or morbidity rate which also needs to be highlighted.

5. The rest of the article is extremely well-written and has got a great deal of relevance to the programmes to be initiated in many developing countries. I would, however, like to add that in the field of Appropriate Technology for Health, it need not necessarily be a technology which is backdated or should be only from the locally available material though economics is important; bulk production and mass distribution utilization particularly in large developing countries who at the present have to import at great costs even the basic disability aids have to become more meaningful so that Appropriate Technology is not equated to primitive technology. Also the dissemination of knowledge through para-medical workers (like the Physicians Assistants who are being recognized as players of the Health Care System at the periphery), through technicians who are specially trained in the art of making various appliances and rehabilitation aids should be encouraged. After all, a hearing aid does not need electronic sophistication and cannot be solved unless there is this specific technology available. Neither can many mobility aids be of simple technology, e.g., mobility aids for the paraplegics which would need in driving three-wheelers, which are available by modification of a bicycle rickshaw. Such adaptation using local craftsmen or local technicians would further aid the disabled in the developing world to find a place in the society. Restoration of dignity to man would be an ideal one for many developing countries to adopt since this would entail an acceptance of equality in all levels of status - the disabled with the able-bodied. After all, a person with able body today can be disabled tomorrow and any person can have one of his or her family with the problem that is not only an economic burden but also a physical and the mental torture. The prevention of deformities and prevention of ailments leading to the deformities is as vital and important in the developing world as in the developed and this also needs forceful emphasis and in the 80's, if a plan has to be drawn up for the total tackling of such a problem, it should start with prevention.

Reviewed by: Father Walter McNamara, C.S.Sp.
Terre des Hommes (Sierra Leone)
Freetown, Sierra Leone

The challenge of disability in today's world is clearly brought out in this comprehensive assessment of rehabilitation of the disabled. The guidelines offered for world wide policy formation during the next decade are excellent. The lives of the disabled - the Fourth World as referred to - are concisely focused with adequate emphasis given to the magnitude of the problems in the Third World. The widening gap between the living standards of the majority in rich nations and that of the masses in the poor nations is one of the major threats to world peace and stability. The

disabled of the Third World are alarmingly further removed from their counterparts in more wealthy countries. If the North-South dialogue is to be realistic, the immediate transfer of resources and aid to the disabled of the Third World is an imperative duty, binding on the richer nations. The paper points out clearly the role of appropriate technology in this regard.

The importance of widespread public health education cannot be overestimated in the Third World. This is particularly true for more primitive and illiterate peoples, who see witchcraft, demonic possession and magic as the only accepted causes for sickness, disability and death within their cultures.

Our feelings and treatment of disability in the First World often lack sufficient spiritual or philosophical aspects; thus the positive lessons of disability are often lost entirely. The presence of sickness and disability in the world should serve as a reminder of the intrinsic worth of the person and the transcendence of the human spirit over the mechanical and physiological functions of the body. The key to any realistic approach to the disabled is first to acknowledge this intrinsic worth that they enjoy to the fullest as human beings.

All rehabilitation efforts serve only to affirm this basic aspiration of the individual - to attain self actualization and realization. Through serving the disabled - to realize such self fulfillment - the rehabilitation worker himself succeeds personally in the very same goal. Thus, the disabled and the fit and able can work together as partners attaining the goals of personal human development.

The paper by Susan R. Hammerman offers the means of realizing these spiritual values through rehabilitation programmes and policies as outlined on a global scale for the 1980's.

A review of "The Full Integration of Disabled Persons in Their Society" (By Bruce M. Curtis)

Reviewed by: Seth L. Tetteh-Ocloo, Ph.D.
From Accra, Ghana
(Currently at the Louisiana School for the Deaf, Baton Rouge, Louisiana)

Curtis' paper is revealing and timely. While there has been tremendous progress in the general field of services to the disabled, there has not been as integrated and as uniform an approach to solving problems of the disabled as a consideration of similarities of problems would indicate.

Curtis traces the history of the new awareness of the needs of disabled people, pointing out that this had its roots in the civil rights movement among the general population. As a result of the new awareness there have been programs for the disabled out of which have emerged a few successful disabled people. He laments, however, that the great majority of disabled Americans have not made any significant progress from where they were. The causes of these, Curtis says, are several: Inability of normal people to accept the disabled; inadequately prepared professionals who work with the disabled; unsympathetic employers who would not give the disabled a chance and what Curtis calls professionalism in the field of service to the disabled. By this he means the unwillingness of professionals in the field to allow capable disabled people to service others; claiming instead, that everything must be done by only professionally trained people, a stance which disabled people resent.

Curtis touches on a problem that is worldwide in its scope: National programs are usually begun by "philanthropic" minded citizens and professionals. As the programs expand they turn out disabled people who, without further training can assume the roles played by the professionals. But here a problem arises: is it reasonable, or could one expect, that professionals could train disabled workers to displace them? It appears that consciously or otherwise, alblebodied professionals do guide their clients away from career choices that might threaten their own means of livelihood.

Mr. Curtis' paper notes most of the major contemporary issues in the provision of services to the disabled: such as mainstreaming, comptetiveness as a characteristic of American society, versus the rights of disabled citizens to employment. He argues that numbers and statistics alone in employment are not enough. People need to be more sensitive to the human factor in employment.

The usefulness of Mr. Curtis' discourse lies not so much in the new facts it brings to light, as in its having come from "the horse's own mouth," as the saying goes. What the article lacks in literary finesse, it more than makes up in the depth of feeling and insight the writer brings to his subject. In spite of the advances that have been made in the provision of education and services for the disabled, it remains a sad fact, as Curtis points out, that unemployment and underemployment among disabled citizens is still a big problem, a problem whose full impact in terms of human misery, unfulfilled dreams, and wasted lives, only disabled themselves can truly feel.

One can hope that these revelations of the feelings of the disabled will result in a willingness on the part of the able bodied to allow the disabled greater say and participation in decisions that affect them. The full integration of the disabled into the mainstream of society will become a reality only when people accept the fact that disability knows no bounds; there is no time in life when human beings become immune to all forms of disability. Ability, or more precisely, physical and mental well-being, should not be a cause for disdain and condescension toward the disabled, but a reason to be thankful to the Being who sustains, predisposition to kindness and a willingness to help the less fortunate.

A review of "Information Dissemination in Rehabilitation" (By Elizabeth Pan, Ph.D. and Barbara Duncan)

Reviewed by: Jose Martinez, L.H.D., CRC, Consultant & Professor of Rehabilitation
Hato Rey, Puerto Rico
(A consultant in rehabilitation to a number of Latin American countries)

I srongly believe in the general theme of this paper, "Information Dissemination in Rehabilitation." There is a great deal of new ways, new means, new approaches, and new mechanisms, to face this problem of better informing all interested sectors of the population, in each community, of the latest developments in the rehabilitation field and in up-dating everyone, everywhere.

I support the comment that scattered messages to promote organizatonal activities should be avoided and that people must learn to distinguish between professional public relations and just commercial publicity in the field of the human services.

In my review of this paper, I could not point out to new mechanisms. The literature quoted is already known to those who have been in the field for some years. The recommendations suggested have been, to the best of my understanding, tried on several occasions in different places and could still prove to be useful in some other countries where there is nothing else available.

But, the ideas discussed do not respond to the present needs or to the needs of the future - they are basically present day answers to an old problem - while I am looking for answers which could lead to the most dignified life for our disadvantaged population.

A Seminar to honor the memory of "The First Lady of the Rehabilitation Movement" - Mary E. Switzer, a person who firmly believed that "life is faith and love, but most of all **hope**" - should bring into the rehabilitation scene such ingredients as creativeness, innovation, uniqueness, new demonstrations and new ideas, etc., which characterized her so wonderfully...a Lady who was always ahead of her times.

The paper lacks sufficient information on today's efforts in Latin America to establish an information dissemination center, and other programs, under the "Grupo Latinoamericano de Rehabilitacion Profesional" (GLARP), in Bogota, Colombia, S.A., in collaboration with the Interchurch Coordination Committee for Development Projects, of Holland, (I.C.C.O.), to serve 18 Spanish speaking countries. The idea of using English as a basic language instead of taking into consideration the three most spoken languages in the world today, is not a sound proposition.

I would like to see, at least, one innovative idea in information dissemination in rehabilitation coming out as a result of this Switzer Seminar, for example, the establishment of a computerized mechanism, in different languages, which could be contacted like a "toll-free system" for immediate consultation and reply.

When it comes to rehabilitation, increasing costs and complexities should not become a decisive factor in implementation because "rehabilitacion es una obra de grandes alcances humanos" - because rehabilitation pays...

The Seminar: Retrospect and Prospect

When asked, the blind man requested: "Lord, that I may see." This Seminar was guided in all its phases by the vision of Mary E. Switzer. Her spirit was present in all the discussions and was an incentive to full participation.

Hopefully, what comes through in these pages is the clear understanding that we live in a mutually dependent world. The line between developing and developed countries is a fine one indeed. We sometimes forget how dependent so-called developed countries are upon the developing world for their finely-tuned economics, with their demands for raw materials on the one hand and markets for goods and services on the other.

It is all the more so in human services. We have much to offer the world in our rehabilitation technology---but we also have much to learn. It is important to know that there can be simple solutions at times to apparently complex problems. The emphasis in this seminar has been on sharing--but, above all, on caring. That was Mary.

James F. Garrett, Ph.D.

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